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ABSTRACT

The study reports on the incidence and prevalence of developmental disabilities in Iowa, in conjunction with estimates of the needs of individuals with developmental disabilities and their demand for services. An introductory section outlines the organization of the report and distinguishes among three types of demand for services: potential demand, expressed demand, and unexpressed demand. In the second section, estimates of the prevalence of developmental disabilities in 1985, 1990, and 1995 are presented by age groups (0-17, 18-64, and over 65) and by county. Detailed analyses of the strengths and limitations of data sources, along with an assessment of the reliability and concurrent validity of the estimates, are also presented, and further discussion identifies the estimation bases employed and elaborates on assumptions underlying the projections for 1990 and 1995. The report includes 17 tables and figures and a bibliography. It is recommended that an eligibility determination system be designed and implemented which can provide data to estimate the hidden demand associated with different service alternatives. (JW)

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THE INCIDENCE AND PREVALENCE OF DEVELOPMENTAL DISABILITIES IN IOWA

FINAL REPORT

Prepared by:

John W. Ashbaugh

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THE INCIDENCE AND PREVALENCE OF DEVELOPMENTAL DISABILITIES IN IOWA

FINAL REPORT

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Submitted to:

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June 15, 1986

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I. INTRODUCTION

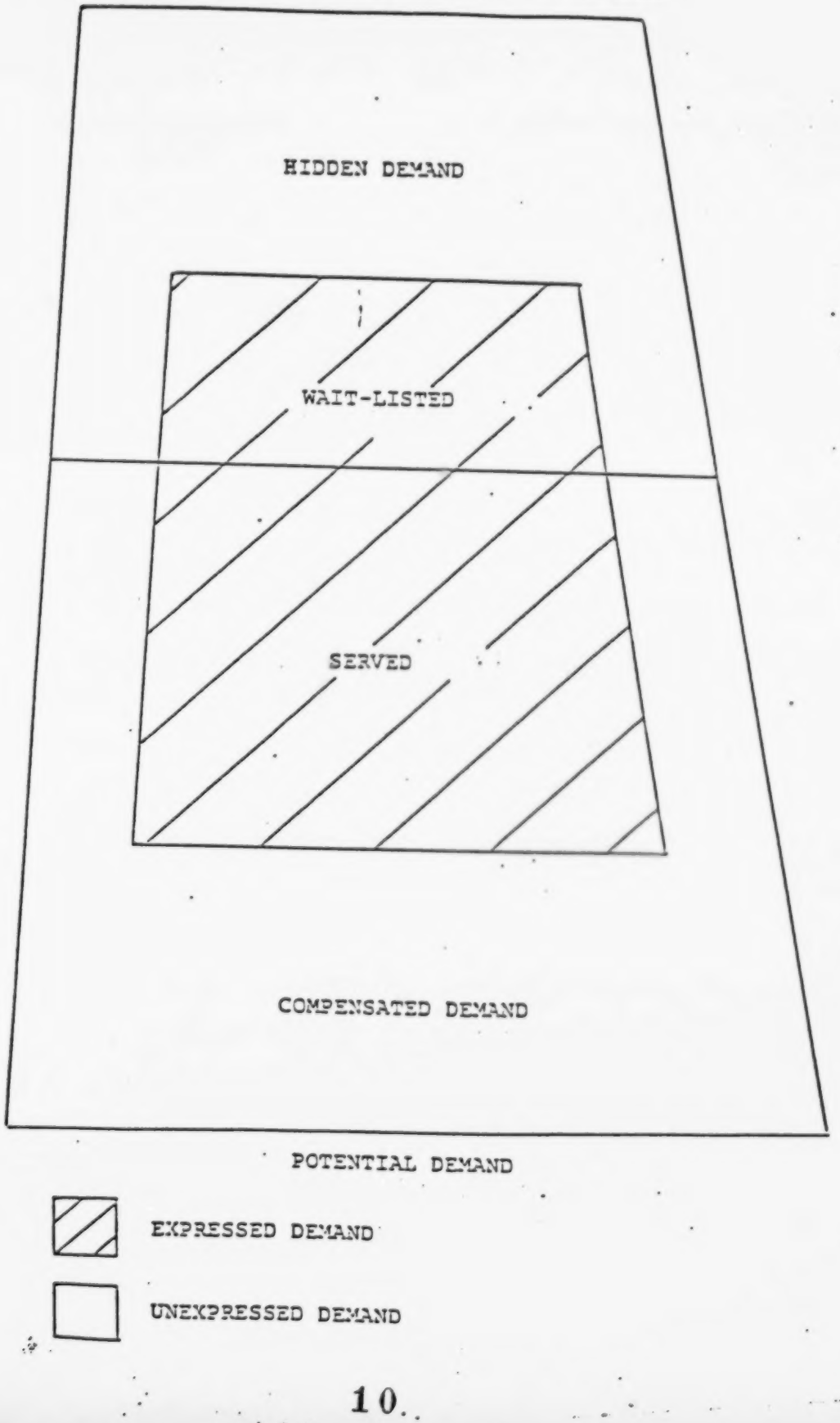
A. Types of Demand

In assessing the probable demand for services to the target population, one must distinguish among the components of the total **potential demand for services** (i.e., all persons meeting the target population definition) including **expressed demand** (i.e., the number of these persons actually participating in developmental disabilities programs), and **unexpressed demand** (i.e., the number of persons not utilizing or demanding public services). Unexpressed demand can be further broken down into **latent demand** part of which is expressed on **waiting lists** (i.e., persons now demanding but not receiving service), and part of which is **hidden or unexpressed**, (i.e., persons not now demanding service but who would demand appropriate services if they had access to them; and **compensated demand** (i.e., persons relying on private supports and who would not presently demand public services even were they made accessible). These categories of demand are illustrated in Figure 1.

Relative to potential demand (i.e., to the total size of the developmentally disabled population) the numbers of persons actually expressing demand for publicly-supported services is quite low. The proportion of the developmentally disabled population receiving publicly-supported services varies markedly from state to state in spite of the fact that the prevalence rates per se should not vary significantly from area to area. For instance, according to 1982 Census of Residential Facilities for mentally retarded citizens (Hauber, Bruininks, Hill, Lakin

FIGURE 1

Demand for Services: A Conceptual Diagram



and White, 1984), Nevada reports only 34.2 beds per 100,000 population, while North Dakota reports 104.2. This distinct difference lends support to the notion that the level of utilization of publicly-funded residential day and support services alternatives is less affected by changes in the overall size of the developmentally disabled population (potential demand) than by changes in availability and adequacy of private services and supports and in the supply of acceptable publicly-funded alternatives.

It is important to recognize that latent demand will surface as new residential and related support services, designed to satisfy known or expressed demand, are established. This additional demand is generated by virtue of the added visibility and accessibility of these services, and the implicit message that such alternatives represent available and acceptable alternatives to family caregivers. In other words, the level of hidden versus compensated demand is not only a function of the adequacy of private residential services and supports, but of the availability of acceptable alternatives.

The state, as a marketer of services for persons with developmental disabilities has the ability to generate and shape demand for these services. Forty years ago demand for services was channeled into institutions. More recently Iowa, like most other states, has channeled this demand into community residences. In future years, respite care and other family support services hold promise to redirect some of this residential service demand into residential supports for those

families seeking relief and support rather than separate residential arrangements for their disabled dependents.

Estimates of the hidden demand for services can be improved through the systematic analyses of information from providers on the number of persons awaiting service. The Division of Mental Health/Mental Retardation/Developmental Disabilities (MH/MR/DD) sponsored a survey of providers of service to persons with developmental disabilities in Iowa in order to obtain such information.* This survey was entitled Update Questionnaire for 1985-86, Iowa Directory of Services for Persons with Developmental Disabilities.

Two-hundred and forty providers gave sufficient information to be included in the compilation of the numbers of persons awaiting service by type of service and relative urgency. The results are summarized in Appendix D. This analysis provides some indication of the relative demand for different types of service overall and the relative urgency of this demand. However, it is not sufficient to indicate absolute estimates of demand. This is because not all providers responded, and it is not possible to determine whether the waiting lists of those responding could be taken to fairly represent the waiting lists of those providers not responding. Moreover, because the providers did not indicate the current living situation and the

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* Source: Memorandum from: Tim Carroll, Divison of MH/MR/DD to John Ashbaugh, Human Services Research Institute, "Waiting List Data from the U.A.F. Developmental Disabilities Update Questionnaire (February 25, 1986).

service status of the individuals identified, it is not possible to distinguish those already served in institutional or community service settings -- albeit inadequately or inappropriately in the judgement of the providers surveyed -- from those unserved.

Reasonably accurate estimates of the hidden demand associated with different service alternatives are best made from studying service supply/demand relationships over a period of years using data from an eligibility determination system such as that outlined below:

(1) All persons seeking placement in state funded Institutions or community living facilities or day services are required to:

-- complete an application for services. The application should seek information on the urgency of the client's situation as well as on the client's level-of-functioning

-- consent to more thorough evaluation upon selection for placement, with placements made according to an established set of state priorty criteria reflecting both client need and the urgency of the caregiver/client situation.

(2) Persons currently served should also be evaluated periodically (preferably annually) in order to assess their level of functioning and service needs (logically as part of the individual habilitation planning process).

(3) The level of functioning evaluations should be done using a standardized individual client evaluation instrument such as the Individualized Client Assessment Profile (ICAP) employed in the Enumeration Study.

(4) These evaluation scores should be incorporated as part of the state's information system in order to allow for ready analysis in support of MH/MR/DD Planning.

(5) Over time these data will allow developmental disabilities planners to identify trends in service demand, and to better gauge the nature and extent of unmet service needs in Iowa.

We recommend that the Divison of Mental Health/Mental

Retardation/Developmental Disabilities design, develop and implement such a system.*

In the absence of these data, we can only make the following educated guesses (assumptions) about the latent demand associated with the addition of community-based residential, day, and client support services. Generally, we project that:

- **the latent demand for residential and day services will increase with increases in client levels of functioning.** While private or personal care networks can accommodate persons regardless of the nature or severity of the disability, surveys of families indicate (as one might expect) that parents, families and guardians of profoundly disabled and medically involved individuals particularly of individuals with severe behavior problems (such as those comprising the target populations), are forced to turn to publicly-funded residential services and supports more frequently than are those whose dependents are less severely disabled, thus they are known to the DD system. Conversely, many less severely disabled individuals have never come to demand publicly-supported services thought they might given the opportunity.

- **the latent demand for client support services other than respite and attendant care will derive primarily from clients in residential and day services.** A finding in the Virginia survey (Agosta, 1985) lending support to this assumption, was that those families already receiving services cited more services as needed than those who did not have clients currently in service. It is largely the professional care givers who direct clients to these services.

- **the latent demand for respite and attendant care is appreciable.** The total magnitude of this latent demand is difficult to chart as state caps on the amount of service available artifically truncate this demand. State caps largely predetermine the demand expressed for these services.

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* A prototype may be found in the State of Maryland. For information contact: Michael Smull or Michael Sachs, Ph.D. Walter P. Carter Center, 630 West Fayette Street, Baltimore, MD 21201 (301) 528-2140.

B. Organization of the Report

Part II first discusses the general concepts of incidence and prevalence of developmental disabilities (Section A). Based on data from a combination of sources, Section B presents the estimated prevalence rates and prevalence of developmental disabilities in Iowa, statewide, by district and county, both current and projected. This information is presented in Table and graphic form. Discussion follows on the strengths and limitations of the estimation methods, those used and other methods considered (Sections C through H). Section I includes an assessment of the reliability and concurrent validity of the estimates, and the identification of the estimation bases employed. Section J elaborates on the assumptions underlying the projections of the size of developmentally disabled population in Iowa in the years 1990 and 1995. Appendix A includes a biblography. Appendix B defines the criteria employed in identifying persons with developmental disabilities from the results of the 1976 Survey of Income and Education. Appendix C explains how HSRI used Social Security Data to estimate the numbers of persons on the SSI/SSDI rolls for reason of a developmental disability in the state. Appendix D contains a compilation of the numbers of persons with developmental disabilities in Iowa awaiting service by type of demand as identified by 240 agencies responding to the University Affiliated Facility's Survey of Providers of Service to Persons with Developmental Disabilities in Iowa. It is important to note that because the observed prevalence of developmental

disabilities varies with age, the tables of estimated prevalence rates presented in this report are age-adjusted. In other words, the prevalence rates shown for each age category are based upon the size of the general population within that age bracket.

II. POTENTIAL SERVICE DEMAND

A. General Concepts of Incidence and Prevalence

The size of the developmentally disabled population can be represented in terms of incidence and prevalence. Incidence refers to the number of new cases that are manifest during a specified period of time. Incidence rates represent the number of new cases occurring during a specified period of time relative to the number of persons at risk during the same period of time.

Prevalence refers to the number of cases (whether old or new) that are present in a population for a designated time interval or point in time. Prevalence rates represent the total number of cases present in the population relative to the total population.

Incidence and prevalence are interrelated. Prevalence rates vary as a function of the incidence and duration of cases. Theoretically, one could estimate the prevalence of disorders (cases) indirectly from estimates of case incidence and duration. However, reliable information on the expected duration or life expectancy of persons with mental retardation and related developmental disabilities is scant, making prevalence rates the measures of choice.

Few if any states can afford to mount epidemiologic surveys or registries comprehensive enough and of sufficient size to yield valid and reliable estimates of the incidence and prevalence of most developmental disabilities. This is particularly true in less populous states such as Iowa. Consequently, estimates are derived using a variety of national

and extra-state surveys and registries. The Human Services Research Institute made use of the following sources in compiling these estimates of the incidence and prevalence of developmental disabilities in the state of Iowa:

(1) National and state-specific estimates of the prevalence of the developmentally disabled population with mental retardation ages 6 and above, based on the 1976 Survey of Income and Education (Gollay, 1981);

(2) State-specific estimates of the numbers of developmentally disabled persons residing in institutions and other group quarters in Iowa based on the 1980 Census of Population.

(3) Estimates of the numbers of persons with developmental disabilities in Iowa based on counts of the numbers of children and adult childhood beneficiaries awarded benefits by diagnosis under the Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) programs together with estimates of the rate of participation in the SSI and SSDI programs among persons with developmental disabilities in Iowa as obtained from the Enumeration Study.

(4) Estimates of the prevalence of developmental disabilities among infants and pre-schoolers based on counts of the numbers of infants and preschoolers (ages 0-5) on high risk infant registries in those states having mandates to serve disabled children from birth;

(5) Estimates of the prevalence of developmental disabilities among infants and pre-schoolers based on epidemiologic data on the incidence and mortality of selected medical conditions that lead to developmental disabilities;

(6) Estimates of the prevalence of selected categorical disabilities (mental retardation, epilepsy, cerebral palsy, and autism) derived primarily from studies compiled by Kiely and Lubin (1983), Farber (1970), Abramowicz and Richardson (1975), and Kiely, Lubin and Kiely (1984);

As will be apparent in our discussion of these estimates, they are all of limited validity, reliability and scope. However, by analyzing these estimates in combination, it was possible to arrive at a more complete picture of the

developmentally disabled population in Iowa than would otherwise have been possible, and to validate concurrently these independent estimates (i.e., to assess the probable validity and reliability of independent estimates according to their degree of consistency).

B. Summary

Estimates of the prevalence and prevalence rates (per 1,000) of persons with mental retardation and other developmental disabilities by age in Iowa are shown in Tables 1A (1985), 1B (1990), and 1C (1995).

As explained in Subsection II.I and as noted in the table footnotes, these estimates derive from a number of different bases: 1) the Iowa Enumeration Survey conducted pursuant to the Bill of Rights Legislation, 2) data on disabled participants in the Supplemental Security Income and Social Security Disability Insurance Programs, 3) the 1976 Survey of Income and Education, and 4) the 1980 Census of Persons in Institutions and Other Group Quarters. Still other sources were considered and estimates were developed based on these sources as well. The major strengths and limitations of all sources are discussed.

Estimates of the number of persons with mental retardation and other developmental disabilities by age, by planning district are shown in Table 2A (1985), B (1990), C (1995). Figure 2 displays a map of Iowa divided by Human Services District and lists counties by district.

Table 2D presents estimates of the number of persons with developmental disabilities by county. The distribution of the

developmentally disabled population by county is assumed to correspond to the known distribution of all disabled children on the SSI rolls as of December 1983 and of all disabled adults on the SSDI rolls for reason of a disability identified in childhood as of December, 1984. The persons on the SSI and SSDI rolls represent two thirds of Iowa's developmentally disabled population. While the SSI/SSDI basis of distributing the developmentally disabled population estimates by county is considered to be the best available, estimates at this level of disaggregation are open to considerable error, more so in less populous than more populous counties. The accuracy of these estimates should be considered and even adjusted as appropriate in light of esoteric knowledge of factors which may artifically raise or lower the estimates in particular counties (e.g., the presence or absence of large residential programs). Table 13 presents general population projections by age for the years 1985, 1990, and 1995 -- statewide and by region -- on which HSRI's projections of the size of the developmentally disabled population are based.

TABLE 1

ESTIMATED PREVALENCE AND PREVALENCE RATES (PER 1,000 GENERAL POPULATION) OF MENTAL RETARDATION AND OTHER DEVELOPMENTAL DISABILITIES IN IOWA BY AGE

TABLE 1A

1985

		PREVALENCE RATES (PER 1,000 GENERAL POPULATION)			PREVALENCE		
AGE	Gen Pop	All DD	MR/DD	Other DD	All DD	MR/DD	Other DD
Total, all ages	2,905,400				20,334	16,411	3,943
0-17	793,140	7.41	5.69	1.72	5,878	4,512	1,366
18-64	1,699,260	7.90	6.49	1.41	13,421	11,032	2,389
65+	412,800	2.56	2.10	0.46	1,055	867	188

TABLE 1B

1990

		PREVALENCE RATES (PER 1,000 GENERAL POPULATION)			PREVALENCE		
AGE	Gen Pop	All DD	MR/DD	Other DD	All DD	MR/DD	Other DD
Total, all ages	2,913,500				20,337	16,395	3,942
0-17	799,540	7.41	5.69	1.72	5,925	4,548	1,377
18-64	1,686,360	7.90	6.49	1.41	13,319	10,948	2,371
65+	427,600	2.56	2.10	0.46	1,093	898	195

TABLE 1C

1995

		PREVALENCE RATES (PER 1,000 GENERAL POPULATION)			PREVALENCE		
AGE	Gen Pop	All DD	MR/DD	Other DD	All DD	MR/DD	Other DD
Total, all ages	2,931,800				20,449	16,486	3,963
0-17	801,400	7.41	5.69	1.72	5,939	4,559	1,380
18-64	1,696,800	7.90	6.49	1.41	13,402	11,016	2,386
65+	433,600	2.56	2.10	0.46	1,108	911	197

TABLE 2

ESTIMATED NUMBER OF PERSONS WITH MENTAL RETARDATION
AND OTHER DEVELOPMENTAL DISABILITIES (OTHER THAN MENTAL ILLNESS)
IN IOWA BY AGE AND DISTRICT

TABLE 2A

1985

DISTRICT	AGE AND TYPE OF DISABILITY: All Ages ALL DD	All Ages MR	All Ages OTH DD	1-17 ALL DD	1-17 MR	1-17 OTH DD	18-64 ALL DD	18-64 MR	18-64 OTH DD	65+ ALL DD	65+ MR	65+ OTH DD
1	2,130	1,718	413	615	472	143	1,405	1,155	250	110	91	20
2	1,812	1,461	351	523	402	122	1,195	982	213	94	77	17
3	2,269	1,830	440	655	503	152	1,496	1,230	266	118	97	21
4	2,634	2,124	510	761	584	177	1,737	1,428	309	137	112	24
5	2,455	1,979	475	709	544	165	1,618	1,330	288	127	105	23
6	4,301	3,468	833	1,242	953	289	2,836	2,331	505	223	183	40
7	2,970	2,394	575	858	658	199	1,958	1,610	349	154	126	27
8	1,783	1,438	345	515	395	120	1,176	966	209	92	76	16
TOTALS	20,354	16,411	3,943	5,878	4,512	1,366	13,421	11,032	2,389	1,055	867	188

TABLE 2B

1990

DISTRICT	AGE AND TYPE OF DISABILITY: All Ages ALL DD	All Ages MR	All Ages OTH DD	1-17 ALL DD	1-17 MR	1-17 OTH DD	18-64 ALL DD	18-64 MR	18-64 OTH DD	65+ ALL DD	65+ MR	65+ OTH DD
1	2,122	1,710	412	631	485	147	1,369	1,125	244	122	100	22
2	1,774	1,438	344	523	401	121	1,147	943	204	104	84	19
3	2,248	1,812	436	659	506	153	1,458	1,199	260	130	107	23
4	2,667	2,151	516	765	587	178	1,750	1,439	312	152	125	27
5	2,514	2,028	486	709	544	165	1,661	1,365	296	143	118	26
6	4,348	3,505	842	1,259	966	293	2,840	2,334	505	249	205	44
7	2,965	2,389	575	872	669	203	1,925	1,583	343	167	138	30
8	1,714	1,381	333	510	392	119	1,143	939	203	62	51	11
TOTALS	20,352	16,486	3,945	5,929	4,551	1,379	13,293	10,927	2,366	1,130	929	201

TABLE 2C

1995

DISTRICT	AGE AND TYPE OF DISABILITY: All Ages ALL DD	All Ages MR	All Ages OTH DD	1-17 ALL DD	1-17 MR	1-17 OTH DD	18-64 ALL DD	18-64 MR	18-64 OTH DD	65+ ALL DD	65+ MR	65+ OTH DD
1	2,132	1,718	414	631	484	147	1,377	1,132	245	124	102	22
2	1,757	1,461	352	514	412	125	1,128	963	209	104	87	19
3	2,248	1,830	441	662	516	156	1,476	1,206	261	130	109	24
4	2,730	2,124	512	773	598	181	1,800	1,480	383	157	126	27
5	2,467	1,979	477	714	558	169	1,606	1,324	282	147	117	25
6	4,424	3,469	835	1,264	977	296	2,902	2,386	495	259	206	45
7	2,992	2,395	577	880	675	204	1,944	1,578	342	169	142	31
8	1,716	1,438	346	585	405	123	1,150	948	205	60	85	18
TOTALS	20,486	16,414	3,953	5,942	4,624	1,400	13,393	10,816	2,342	1,150	974	211

TABLE 20

ESTIMATED NUMBER OF PERSONS WITH DEVELOPMENTAL DISABILITIES
IN IOWA BY COUNTY, 1985

COUNTY	DISTRICT	All DD	MR/DD	Other DD
STATEWIDE		20,354	16,411	3,943
BUENA VISTA	1	156	126	30
CHEROKEE	1	64	51	12
CLAY	1	64	51	12
DICKINSON	1	87	70	17
EMMET	1	87	70	17
IDA	1	29	23	6
LYON	1	46	37	9
MONONA	1	64	51	12
OBRIEN	1	81	65	16
OSCEOLA	1	110	89	21
PALO ALTO	1	64	51	12
PLYMOUTH	1	81	65	16
SIOUX	1	260	210	50
WOODBURY	1	938	756	182
CALHOUN	2	58	47	11
CERRO GORDO	2	295	238	57
FLOYD	2	417	336	81
FRANKLIN	2	98	79	19
HAMILTON	2	58	47	11
HANCOCK	2	52	42	10
HUMBOLT	2	23	19	4
KOSSUTH	2	185	149	36
MITCHELL	2	35	28	7
POCAHONTAS	2	35	28	7
WEBSTER	2	289	233	56
WINNEBAGO	2	151	121	29
WORTH	2	35	28	7
WRIGHT	2	81	65	16
ALLAMAKEE	3	64	51	12
BLACK HAWK	3	1,407	1,134	272
BREMER	3	104	84	20
BUCHANAN	3	156	126	30
BUTLER	3	69	56	13
CHICKASAW	3	58	47	11
CLAYTON	3	93	75	18
FAYETTE	3	139	112	27
GRUNDY	3	17	14	3
HOWARD	3	81	65	16
WINNESHIEK	3	81	65	16
CEDAR	4	46	37	9
CLINTON	4	278	224	54
DELAWARE	4	87	70	17
DUBUQUE	4	854	672	161
JACKSON	4	139	112	27
MUSCATINE	4	243	196	47
SCOTT	4	1,007	812	195
BENTON	5	98	79	19
HARDIN	5	110	89	21
IOWA	5	52	42	10
JOHNSON	5	463	373	90
JONES	5	69	56	13
LINN	5	1,100	887	213
MARSHALL	5	342	275	66
POWESHIEK	5	58	47	11
TAMA	5	69	56	13
WASHINGTON	5	93	75	18
BOONE	6	399	322	77
DALLAS	6	168	135	33
JASPER	6	214	173	41
MADISON	6	46	37	9
MARION	6	237	191	46
POLK	6	2,790	2,250	541
STORY	6	255	205	49
WARREN	6	191	154	37
ADAIR	7	52	42	10
ADAMS	7	23	19	4
AUDOBON	7	12	9	2
CARROLL	7	93	75	18
CASS	7	58	47	11
CLARK	7	52	42	10
CRAWFORD	7	52	42	10
DECATUR	7	41	33	8
FREMONT	7	87	70	17
GREENE	7	69	56	13
GUTHRIE	7	64	51	12
HARRISON	7	75	61	15
MILLS	7	920	742	178
MONTGOMERY	7	35	28	7
PAGE	7	116	93	22
POTTAWATTAMI	7	845	681	164
RINGOLD	7	23	19	4
SAC	7	58	47	11
SHELBY	7	139	112	27
TAYLOR	7	58	47	11
UNION	7	98	79	19
APPANOOSE	8	162	131	31
DAVIS	8	29	23	6
DES MOINES	8	243	196	47
HENRY	8	98	79	19
JEFFERSON	8	46	37	9
KEOKUK	8	104	84	20
LEE	8	272	219	53
LOUISA	8	58	47	11
LUCAS	8	75	61	15
MAHASKA	8	110	89	21
MONROE	8	58	47	11
VANBUREN	8	58	47	11
WAPELLO	8	417	336	81
WAYNE	8	52	42	10

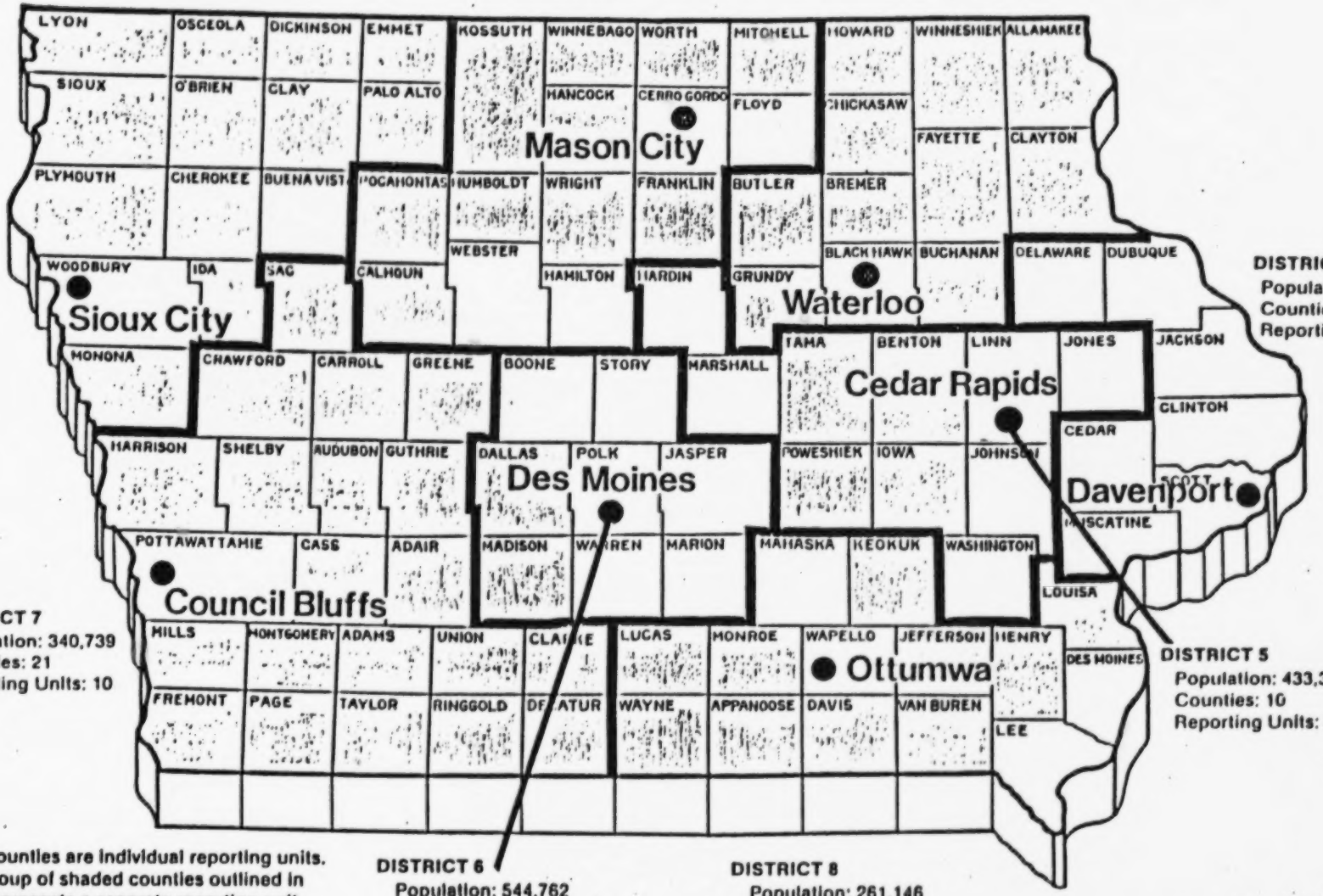
FIGURE 2

Department of Human Services Districts and District Offices

DISTRICT 1
Population: 313,553
Counties: 14
Reporting Units: 8

DISTRICT 2
Population: 268,520
Counties: 14
Reporting Units: 9

DISTRICT 3
Population: 327,836
Counties: 11
Reporting Units: 6



DISTRICT 4
Population: 400,996
Counties: 7
Reporting Units: 7

DISTRICT 5
Population: 433,379
Counties: 10
Reporting Units: 8

DISTRICT 6
Population: 544,762
Counties: 8
Reporting Units: 7

DISTRICT 7
Population: 340,739
Counties: 21
Reporting Units: 10

DISTRICT 8
Population: 261,146
Counties: 14
Reporting Units: 9

KEY:
White counties are individual reporting units. Each group of shaded counties outlined in white represents a separate reporting unit, sharing a county director and perhaps a technical supervisor.

C. Estimates Based on the 1976 Survey of Income and Education (SIE)

Table 3A presents state-specific estimates of the prevalence rates (per 1,000) of developmental disabilities among the civilian non-institutionalized population in Iowa by type of impairment. Persons were identified as developmentally disabled based on identifying information obtained by the survey (specific identification criteria are displayed in Appendix A). To the extent possible, such information was interpreted in light of the federal "functional" definition of developmental disability. According to this definition, the term "developmental disability" means a severe, chronic disability that:

- is attributable to a mental or physical impairment or combination of mental and physical impairments;
- is manifested before the person attains the age twenty-two;
- is likely to continue indefinitely;
- results in substantial functional limitations in three or more of the following areas of major life activity;
  - -- self care,
  - -- receptive and expressive language,
  - -- learning,
  - -- mobility,
  - -- self-direction,
  - -- capacity for independent living, and
  - -- economic self-sufficiency; and
- reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services that are of lifelong or extended duration and are individually planned and coordinated.

Table 3B presents estimates of the prevalence rates (per 1,000) of mental retardation and other developmentally disabilities among the civilian noninstitutionalized population by age. In compiling this table, the Iowa-specific prevalence

TABLE 3A

ESTIMATED PREVALENCE RATES (PER 1,000) OF DEVELOPMENTAL DISABILITIES, BY TYPE OF IMPAIRMENT: CIVILIAN NONINSTITUTIONALIZED POPULATION, 1976

	SEVERE MR	SER EMOT DIS	SENSORY IMP	PHYSICAL IMP	TOTAL DD
Prevalence	4.2	1.0	1.3	3.1	9.6
67% range*	3.2 - 5.2	0.5 - 1.5	0.8 - 1.8	2.3 - 3.9	8.1 - 11.1
95% range**	2.2 - 6.2	0.1 - 1.9	0.3 - 2.3	1.5 - 4.7	6.7 - 12.5

* 67% probability that the "true" number falls within this range.
** 95% probability that the "true" number falls within this range.

Source: Based on estimates prepared by Gollay and Associates (1980).

TABLE 3B

ESTIMATED PREVALENCE RATES (PER 1,000) OF MENTAL RETARDATION AND OTHER DEVELOPMENTAL DISABILITIES, BY AGE: CIVILIAN NONINSTITUTIONALIZED POPULATION, 1976

	AGE:					
IMPAIRMENT:	All ages	3 - 5	6 - 17	18 - 21	22 - 64	65+
DD/MR	4.2	2.6	5.1	5.8	1.5	1.7
DD/NON-MR	5.6	3.5	14.8	4.2	0.4	10.7

rates were assumed to reflect national age percentages and were distributed according to these percentages.

The Survey of Income and Education estimates are based on a 1976 sample survey of 151,170 households containing 160,975 families and 440,815 individuals. It is by far the largest survey conducted in the past decade that contains the basic information necessary to identify adults and children with developmental disabilities.

The overriding problem with the Survey of Income and Education, as with all national surveys, is the large sampling error associated with estimating the size of the developmentally disabled population and subpopulations, particularly within less populous states (such as Iowa) and particularly by age and sex -- two important breakdowns known to be associated with significant differences in the prevalence of particular developmental disabilities. The low reliability of the state estimates is indicated by the large confidence intervals associated with estimates of the size of the developmentally disabled population by impairment category in Iowa as shown in Table 3A.

Other design limitations are that the Survey of Income and Education does not cover those infants and children under age three, and covers only the civilian noninstitutionalized population. Information on the chronicity of disabling conditions is limited, and there is no breakout available by type of developmental disability (e.g., cerebral palsy, autism, epilepsy, or spina bifida).

These and lesser limitations notwithstanding, the Survey of

Income and Education is the only reasonably current national survey with a state-sensitive sampling scheme that allows for state-specific estimates, and that includes the wide range of information on activity limitations needed to identify persons as developmentally disabled, particularly mentally retarded, according to a "functional definition."

D. Estimates of the Number of Developmentally Disabled Persons in Iowa Institutions Based on the 1980 Census of Population: Persons in Institutions and Other Group Quarters

The Census covers persons living in the following types of institutions: correctional facilities, mental (psychiatric) hospitals, residential treatment centers, tuberculosis hospitals, other chronic disease hospitals, homes for the aged, homes and schools for the mentally handicapped (public and private), homes and schools for the physically handicapped, homes for dependent and neglected children, homes for unwed mothers, training schools for juvenile delinquents (public and private), and detention homes; and persons living in other group quarters -- rooming houses (houses with nine residents or more not related to the householder), temporary motels, hotels, Y's charging four dollars or more, military barracks, college dormitories, communes, halfway houses, religious group quarters, workers dorms, low cost transient quarters, general hospital or nurses dormitories, institutional staff quarters.

Table 4 presents the estimated prevalence rate (per 1,000 general population) of developmentally disabled persons with mental retardation and other handicaps in Iowa by age living in institutions designed for handicapped persons, specifically (i.e., psychiatric hospitals and residential treatment centers, tuberculosis hospitals and other chronic disease hospitals, homes and schools for the mentally handicapped, and homes and schools for the physically handicapped). It was assumed that all persons living in psychiatric hosptials and residential treatment centers were emotionally disturbed, and all living in homes and schools

TABLE 4

ESTIMATED PREVALENCE RATES (PER 1,000) OF MENTAL RETARDATION AND OTHER DEVELOPMENTAL DISABILITIES IN IOWA INSTITUTIONS AND OTHER GROUP QUARTERS, BY AGE, 1980

IMPAIRMENT:	AGE: 3 - 5	6 - 17	18 - 21	22 - 64	65+
DD/MR	0.05	0.6	1.6	1.1	0.4
DD/NON-MR	0.10	1.1	1.6	0.4	0.5

Source: 1980 Census of Population: Persons in Institutions and Other Group Quarters, Vol. 2, Subject Reports (1984).

for the mentally handicapped were mentally retarded.

E. Estimates Based on Social Security Data and the Enumeration Study

These estimates are developed using the Quadrant Method, so named because it uses known estimates of the size of three segments (quadrants) of the developmentally disabled population in the state to estimate the size of fourth unknown quadrant.* As shown in Figure 3D, the quadrants are divided according to SSI and SSDI participation and participation in the enumeration study.

The unknown quadrant consists of those persons with developmental disabilities in the state who neither participate in the SSI or SSDI programs and who are not identified in the enumeration study (Figure 3D, quadrant D). This is done based on the assumption (or variation thereof) that persons with developmental disabilities participate in the SSI/SSDI entitlement programs at the same rate regardless of whether they are known or unknown to the state developmental disabilities system. More specifically, in the case of Iowa, it is assumed

* Note: Because eligibility determination procedures are known to differ to some extent from region to region in the case of Social Security Disability Insurance, and from state to state in the case of Supplemental Security Income, the Quadrant method can only be applied on a state by state basis. In this way the estimates are not affected by whether a state or region has relatively strict or liberal SSI or SSDI eligiblity requirements. The formula is such that liberal jurisdictions will show more individuals with developmental disabilities as participating in the SSI and SSDI programs (quadrants A and B) and fewer not participating (quadrants C and D). In conservative jurisdictions, fewer individuals with developmental disabilities would be identified as participating in the SSI or SSDI program (quadrants A and B), while more would be indicated as not participating (quadrants C and D).

that the ratio of the number of developmentally disabled individuals not identified in the enumeration study and not participating in the SSI or SSDI programs (quadrant D) to the number of developmentally disabled persons not identified in the enumeration study but participating in the SSI or SSDI programs (quadrant B) is the same as the ratio of the number of developmentally disabled persons identified in the enumeration study as not participating in the SSI or SSDI programs (quadrant C) to the number of developmentally disabled persons identified in the enumeration study as participating in the SSI or SSDI programs (quadrant A). In short, it is assumed that the rate of participation in SSI/SSDI programs among developmentally disabled persons found in the enumeration study sample fairly represents the rate of participation in the SSI and SSDI programs among all developmentally disabled persons in Iowa.

The sum of quadrants A and C, the number of clients by SSI and SSDI status, was obtained from the enumeration survey of individuals. These individuals were identified through the voluntary efforts of over 700 agencies in Iowa and through an extensive public information campaign. The assessment instrument employed was the Inventory for Client and Agency Plans (ICAP). This instrument was developed at the University of Minnesota. Quadrant B is calculated by subtracting the number of developmentally disabled persons identified in the enumeration study as participating in the SSI or SSDI programs (quadrant A) from the total number of persons estimated by HSRI to be participating statewide (quadrants A and B); these estimates are

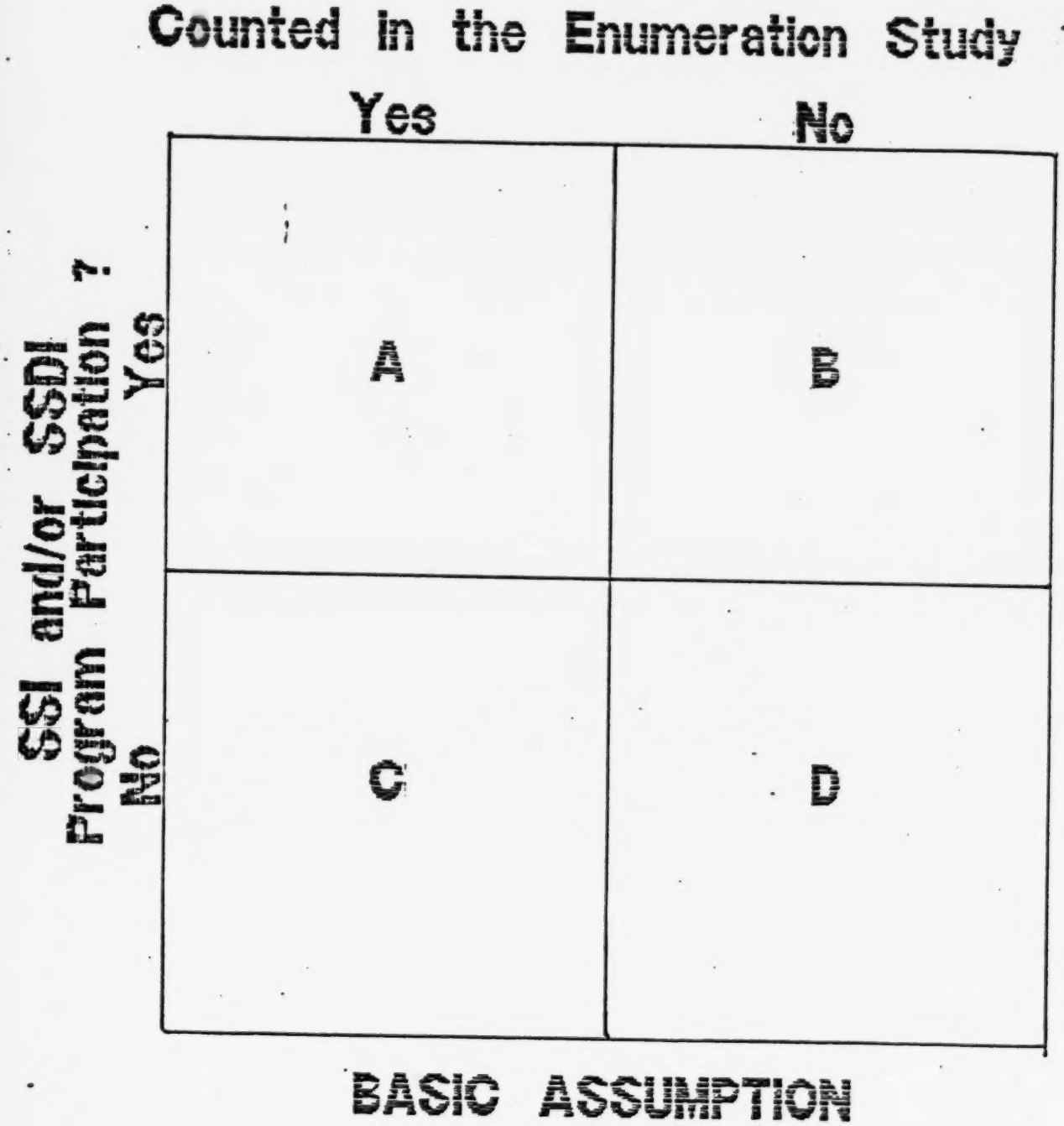
calculated for Iowa by the Human Services Research Institute using data obtained from the Social Security Administration. These estimates are presented in Table 5.

These source data are sufficiently detailed to allow estimates for three developmentally disabled subpopulations:

1) children (under age 18) with mental retardation
2) children (under age 18) with other developmental disabilities
3) adults (ages 18-64) with mental retardation

These three subpopulation estimates are shown in Figures 3B - 3D. The size of the fourth subpopulation, adults with other developmental disabilities, cannot be estimated directly using the Quadrant Method. This is because unlike mental retardation, it cannot be assumed that HSRI's estimate of the number of adults with disabilities other than mental retardation includes only persons with disabilities contracted in childhood and who thus qualify as "developmentally disabled." The estimation procedure is further explained in Appendix C.

Quadrant Method for Estimating the Size of the Developmentally Disabled Population.



BASIC ASSUMPTION

$B/D = A/C$

$D = B(C/A)$

FIGURE 3A

FIGURE 3B

Estimated Number Of Developmentally Disabled Children (under age 18) With Mental Retardation, by Enumeration Survey and SSI/SSDI Participation Status, December 1984

Identified In The Enumeration Study?

SSI/SSDI Rolls?	YES	NO	Estimated Number ON SSI/SSDI Rolls*
YES	A SSI 375 SSDI BOTH TOTAL	B 1505	1880
NO	C 525	D 2107	

Total (A+B+C+D) 4512

*HSRI Estimates as of December 1984, See Appendix C For Explanation

FIGURE 3C

Estimated Number Of Developmentally Disabled Children (under age 18) With Other Developmental Disabilities, Total And By Enumeration Survey And SSI/SSDI Participation Status, December, 1984.

SSI/SSDI Rolls?	Identified In The Enumeration Study? YES	Identified In The Enumeration Study? NO	Estimated Number ON SSI/SSDI Rolls*
YES	A SSI 134 SSDI BOTH TOTAL	B 365	499
NO	C 233	D 634	

Total (A+B+C+D) 1366

*HSRI Estimates as of December 1984, See Appendix C For Explanation

FIGURE 3D

Estimated Number Of Developmentally Disabled Adults (ages 18-64) With Mental Retardation, Total And By Enumeration Survey And SSI/SSDI Participation Status, December 1984

SSI/SSDI Rolls?	Identified In The Enumeration Study? YES	Identified In The Enumeration Study? NO	Estimated Number ON SSI/SSDI Rolls
YES	A	B	
	SSI 2608		2821
	SSDI 1857		4323
	BOTH 956		1632**
	TOTAL 5422	3354	8773
NO	C	D	
	1394	862	

Total (A+B+C+D) 11032

*HSRI Estimates as of December 1984, See Appendix C For Explanation

** Estimated; Assumed To Be In The Same Proportion As Both The SSI And SSDI/SSI Proportion Found In The Enumeration Study.

TABLE 5

ESTIMATED NUMBER OF SUPPLEMENTAL SECURITY INCOME(SSI)
AND SOCIAL SECURITY DISABILITY INSURANCE(SSDI)
RECIPIENTS BY TYPE OF DISABILITY IN IOWA, DECEMBER 1984

Type of Recipient:	Type of Disability: Mental Retardation	Other
SSDI Adult	4,453	6,554
SSDI Adult(beneficiary from childhood)	5,666	1,135
SSI Adult	289	20,658
SSI Child	1,880	499

F. Estimates Based on State High Risk Infant Registries

For purposes of developmental disabilities planning, infants and preschool-aged children up to 36 months of age who have a high probability of manifesting a sensory or motor deficit and/or mental handicap are commonly termed medically fragile, at risk of being developmentally disabled. This group includes:

- o children with syndromes that are known to result in later mental retardation and other developmental disabilities;
- o children with identified developmental delays, as determined by a standard assessment.

Identifying these children, is difficult. As Arango (1983) points out, "physicians are reluctant to call a child disabled' until they are certain that what is obviously a developmental delay is not simply a case of slow growth" (p. 19).

Accordingly, obtaining sizeable samples of children under four years of age with particular developmental disabilities can be especially difficult. Many disabilities are not easily detected until a child enters school (e.g., mild mental retardation, learning disabilities), and early diagnostic signs may be attributed to normal developmental lags rather than to disability. As a result, epidemiologists are forced to deal with few identifiable cases in this age range, and sampling error becomes a major issue (Sower and Covert, 1975; Baird and Sadnovnik, 1985).

To obtain prevalence rates for the 0-5 age group, HSRI conducted a telephone survey of those states having high risk infant registries and having mandates to serve disabled children from birth. It was assumed that the registries in these states

would have cause to be more complete than would any registries existing in other states. The results of HSRI's survey of high risk infant registries are shown in Table 6.

TABLE 6

PREVALENCE RATES (PER 1,000 GENERAL POPULATION) OF DISABLING CONDITIONS AMONG CHILDREN AGES 0 - 5

STATE	AGE 0 - 2	AGE 3 - 5
Iowa	6.0	-
Massachusetts	-	10.0
Maryland	4.7	-
Michigan	4.5	10.0
Nebraska	7.3	15.3
New Jersey	-	-
Rhode Island	-	10.0
South Dakota	5.7	-
Median	5.7	10.0

Source: Compilation of data from State High Risk Infant Registries (HSRI, 1985).

G. Estimates of the Prevalence Rates of Developmental Disabilities Among Infants and Children Age Five and Under Based on the Incidence, Associated Mortality, and Probable Disability Associated with Selected Pre- and Post-natal Medical Conditions (Tables 7A & &7B)

HSRI also estimated the number of developmentally disabled children under age six using the available condition-specific incidence and mortality data coupled with some empiric data and the educated guesses of pediatricians and other practitioners in the field on the probability of associated disability (see Tables 7A & 7B). The approach expands upon earlier work done by Arango, Price and Krchmar (1983). As shown in Table 7B, most of these cases are expected to be identified by age three.

The chief limitations of this method are:

- Data available from studies of the incidence, mortality and especially disability rates associated with different medical conditions is quite limited, and these studies often report widely varying rates.
- Infants and children having one disabling condition often have others. There is insufficient epidemiologic data in the case of most disabling conditions to obtain unduplicated counts by factoring-down cases with multiple handicaps.
- The incidence and mortality rates have not been adjusted for ethnicity and socio-economic status (SES) even though the incidence of these developmental disabilities and related mortality rates associated with maternal infections and diseases, fetal alcohol syndrome, birth complications and acquired postnatal factors are known to vary by race and SES (Last, 1986; Mayre, 1982; Morrison and Heady, 1955; Morrison, Heady and Matrix, 1959). Race-specific and socio-economic status (SES)-specific rates would yield more reliable estimates.
- Some conditions are omitted or underrepresented. Included are mostly those conditions having some associated mental deficiency or neurologic impairments.
- More accurate representations of the incidence and mortality associated with developmental disability related conditions could be made by subdividing some of these categories and conditions (e.g., conditions

associated with obstetric complications such as cerebral palsy from conditions such as idiopathic seizure disorders).

TABLE 7b

INCIDENCE OF CONDITIONS LIKELY TO CAUSE DEVELOPMENTAL DISABILITY

Condition	Incidence (Number per 10,000 live births)	Estimated number affected (Annually 45,000 live births/year)	Prenatal mortality	Likelihood that developmental disability will occur	Estimated number of children with developmental disability per year
1. Hereditary causes					
A. Inborn errors of metabolism					
1. PKU (ASTHO, 1984)	.7	3		99% *	3
2. Hypothyroidism (ASTHO, 1984)	2.1	9		42% *	4
3. Histidinemia (Galactosemia, Tay-Sach's, Hunter's, Hurler's syndromes) (Frymr, 1984)	.6	2		10% *	2
B. Structural/functional					
1. Cystic fibrosis (Harwich, Pagano, Gerber & Heskett, 1973)	5	22	8%	100%	5
2. Muscular dystrophy	1 (Boys ages 3-5)	5		100%	5
C. Blood					
1. Rh factor	11	50		10%	5
					24
2. Early influence on embryonic development					
A. Chromosomal abnormality					
1. Down's syndrome (Birth Defects Monitoring Program, 1985)	18	45	26%	100%	33
2. Other autosomal anomalies (Frymr, 1984)	28	98	26%	10%	7
3. Sex chromosome disorders (Klinefelter's) (Frymr, 1984)	28	135	26%	10%	18
4. Non-specific disorders (recessive, X-linked) (Frymr, 1984)	15	68	26%	50%	25
B. Open neural-tube disease					
1. Spina bifida (Birth Defects Monitoring Program, 1985)	10	45		50%	23
C. Maternal diseases (Karlsson and Connor, 1972)					
Diabetes, thyroid, heart, renal, blood diseases	630	2,700	6%	5%	127
D. Maternal infections					
Rubella, cytomegalovirus, toxoplasmosis, venereal diseases (Frymr, 1984)	23	104		5%	5
E. Introduced factors					
Fetal alcohol syndrome	12	54		40%	22
		2,226			252
3. Birth complications					
Prematurity					
Birth weight over 1,500 grams	720	3,235	5%	6%	197
Birth weight under 1,500 grams	50	225	40%	15%	20
					217
4. Acquired postnatal factors					
A. Measles, encephalitis	17 (Children ages 0-4)	77		20%	15
B. Head and spinal cord injury (Anderson & Richards, 1980)	23 (Children ages 0-5)	104		2%	2
					17

* Significantly lower with screening.

TOTALS = 500

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TABLE 7B

ESTIMATED PREVALENCE OF DEVELOPMENTAL DISABILITIES
AMONG CHILDREN AGES 0-5 IN IOWA, 1985

Child born	Disability identified at birth (10%)	Identified first year (10%)	While child is one (30%)	While child is two (30%)	While child is three (10%)	While child is four (5%)	While child is five (5%)	Total prevalence	Children's age
This year	50	—	—	—	—	—	—	50	"Newborns"
Last year	50	50	—	—	—	—	—	100	"Less than 1 year"
2 years ago	50	50	150	—	—	—	—	250	"1 year olds"
3 years ago	50	50	150	150	—	—	—	400	"2 year olds"
4 years ago	50	50	150	150	50	—	—	450	"3 year olds"
5 years ago	50	50	150	150	50	25	—	475	"4 year olds"
6 years ago	50	50	150	150	50	25	15	500	"5 year olds"
								2,225	Total demand

H. Estimates Based on Epidemiological Studies

There are three critical limitations to the usefulness of epidemiologic study data for estimating the size of the developmentally disabled population in a state or substate area.

1) Limited information on dysfunction. They are by design targeted to specific disabling conditions or to particular types of disabling conditions and only rarely capture and report information on activity limitations or levels of functioning -- information essential for services planning. In short, there is insufficient information to distinguish the level of disability associated with these conditions, compromising their utility for classifying persons as having a developmental disability according to a functional definition.

2) Limited coverage. There are hundreds of medical conditions with varying potential to disable those who inherit or contract them. There is a lack of comprehensive data on the prevalence of many of these disorders -- the fundamental problem is their rarity (low incidence and prevalence). Few population studies can obtain enough cases of any given disease to make reliable estimates, and studies based on hospital or clinical samples are difficult to generalize (Gortmaker and Sappenfield 1984).

3) Duplicate counts. As explained below in Subsection H-6, persons who have one developmental disability are likely to have others. Consequently, to obtain an unduplicated count of cases across all developmentally disabling conditions, one cannot simply total categorical estimates but must factor down the estimates by the number of persons having more than one condition. To do so would be extremely difficult if not impossible.

An advantage of categorical estimates, and it is an important advantage, is that there is a need to know for service planning purposes the types of disabling conditions as well as the severity of the associated disabilities. Moreover, an analysis of epidemiologic data over time can provide some basis for projecting increases or decreases in the incidence and prevalence of developmental disabilities.

Accordingly, though HSRI did not use condition-specific,

epidemiologic study data for estimating the size of the developmentally disabled population in Iowa, epidemiologic data was compiled on some of the most common developmental disabilities (mental retardation, epilepsy, cerebral palsy and autism). These data are included to inform planners and advocates in the state concerned with individuals having these particular disabling conditions, and to inform HSRI's projections of the size of the developmentally disabled population in Iowa in the years 1990 and 1995.

Epidemiologic surveys vary in sample design, size, and case identification procedures. Most are also limited in terms of the information available on the extent or severity of the disabling condition and on its duration. Nonetheless, they do provide prevalence estimates by type of disabling condition, and considered together provide a picture of how varied the prevalence of different developmental disabilities can be. Large differences in study estimates are generally attributable to differences in the case finding procedures or to variations in the survey or registry methods used. Many also provide reasonably reliable estimates of age- and sex-specific, prevalence rates. HSRI, in synthesizing the studies reported in the literature, drew heavily from the compilations prepared by Kiely and Lubin (1983), Farber (1968), Abramowicz and Richardson (1975), and Kiely, Lubin and Kiely (1984).

1. Mental Retardation

Mental retardation refers to significantly subaverage (two standard deviations below the mean) general intellectual

functioning according to Intelligence Quotient (IQ) tests, and concurrent deficits in adaptive behavior (according to age-appropriate standards of personal independence and social responsibility), and manifested during the developmental period (prior to age 18) (American Association for Mental Deficiency, 1977).

Most epidemiologic studies of mental retardation confine the measures of mental retardation to the intelligence dimension; few studies examine the adaptive behavior dimension. This is a major drawback for planners since the adaptive behavior scores (functioning levels) tell more about the need for support services than do intelligence scores. In fact, most epidemiologic studies report only two categories of intelligence: mild mental retardation and severe mental retardation, the latter encompassing persons with IQ's below 50 or 55.

a. Severe Mental Retardation (Table 8)

Table 8 summarizes the high, low and median age-adjusted rates (per 1,000) of severe mental retardation reported in those community epidemiologic studies judged reliable based on the reviewers' evaluations of the methods used for case finding and for enumerating the general population.

Persons with severe mental retardation, as opposed to mild mental retardation, require considerable support since these individuals have severe activity limitations (Baird and Sadovnik, 1985). Because severe mental retardation appears to be less subject to socio-economic influences and to demographic

differences than does mild mental retardation, prevalence rate estimates for severe mental retardation tend to be more consistent (Birch et. al., 1970; Abramowicz and Richardson, 1975).

The observed prevalence rate for severe mental retardation varies markedly with age with the highest rates occurring in the early teens (Kiely and Lubin, 1983). There is a consistently higher rate of mental retardation among males than among females owing in part to the role of the "X" chromosone in genetically linked disorders (Kiely and Lubin, 1983; Turner and Oppitz, 1980; Baird and Sadovnik, 1983).

b. Mild Mental Retardation

Estimates of the prevalence of mild retardation vary widely. Unlike the prevalence of severe mental retardation, the prevalence of mild mental retardation appears to be strongly associated with socioeconomic status (Kiely and Lubin, 1983; Richardson & Abramowicz, 1975; Birch et al., 1970; Jackson, 1965). Differences may also be explained by variations in the case identification procedures employed.

Prevalence rates of mild mental retardation based largely on health registers and medical records tend to be relatively low because they exclude a large segment of the mentally retarded population with minimal medical involvement. Prevalence estimates of mild mental retardation based largely on education records and household surveys tend to be much higher since they include the sizeable learning disabled subpopulation, as well as persons with behavior problems -- problems that color rater

TABLE 8

ESTIMATED PREVALENCE RATES (PER 1,000 GENERAL POPULATION) OF SEVERE MENTAL RETARDATION, BY AGE AND SEX, BASED ON EPIDEMIOLOGIC SURVEYS AND REGISTRIES IN AREAS OUTSIDE ICMA

Age/sex	Low	Median	High
0 - 4 years	0.5 Kushlick & Cox, 1967	0.9	3.1 Wing, 1971
5 - 9	1.4 Kushlick, 1961	3.6	4.1 Wing, 1971
10 - 14	2.3 Innes, Kidd & Ross, 1968	3.5	4.4 Lewis, 1929
15 - 19	1.1 Goodman & Tizard, 1962	3.6	4.0 Scally & Mackay, 1964
20 - 29	2.1 Lewis, 1929	2.9	3.9 Scally & Mackay, 1964
30 - 39	1.5 Lewis, 1929	2.1	3.2 Kushlick, 1961
40 - 49	1.2 Lewis, 1929	1.8	2.3 Kushlick, 1961
50 - 59	0.9 Lewis, 1929	1.3	1.8 Kushlick, 1961
60+	0.5 Lewis, 1929	0.6	1.3 Innes, Kidd & Ross, 1968
Male	53% Scally & Mackay, 1964	57%	59% OR State Bd. of Health, 1962
Female	40% OR State Bd. of Health, 1962	43%	46% Scally & Mackay, 1964

judgement of their learning ability (Stanford Research Institute, 1978; Mercer, 1973).

Estimates of the prevalence of mild retardation range from 21 to 25 per thousand (Farber, 1968; Kaufman and Payne, 1975; Maloney and Ward, 1979). However, most of these individuals, while they have IQs from 55-69 (have relatively low scholastic aptitude), are able to achieve independence and personal self sufficiency in their adult years (Charles, 1953; Richardson, 1978), and thus will not demand extraordinary public or private supports.

Tarjan (1970) estimates that only about 20% of these people have some organic impairment. It is only this segment which is likely to show adaptive deficits throughout life and to warrant continuous classification as mentally retarded (Baroff, 1982). In accordance with these judgements, HSRI's estimates of potential demand include only 20% of the mildly retarded population.

2. Epilepsy (Table 9)

Epilepsy is defined to include chronic conditions of the nervous system characterized by recurrent seizures (involuntary motor activity or change in consciousness and behavior) for purposes of estimating the prevalence of rates of the disability (Blackman, 1983). Not included are febrile seizures (precipitated by fever) or single nonrecurrent seizures. Most studies report that 60% to 80% of the cases of epilepsy are grand mal or petit mal seizures which are generalized throughout the body. Less common are local seizures which occur in particular

TABLE 9

ESTIMATED PREVALENCE RATES (PER 1,000 GENERAL POPULATION) OF EPILEPSY, BY AGE AND SEX
BASED ON EPIDEMIOLOGIC SURVEYS AND REGISTRIES IN AREAS OUTSIDE IOWA

Age/sex	Number of sources	Low	Median	High
All ages	(n = 13)	2.6 Majsbort, 1967	4.8	6.2 Hauser & Kurland, 1975
0 - 9 years	(n = 10)	1.1 Majsbort, 1967	3.5	5.8 Kurland, 1959
10 - 19	(n = 8)	3.5 Majsbort, 1967	4.6	6.5 Stanhope, 1972
20 - 29	(n = 10)	3.0 Majsbort, 1967	5.3	14.0 Stanhope, 1972
30 - 39	(n = 11)	2.7 Majsbort, 1967	4.4	8.2 Brewis, 1966
40 - 59	(n = 10)	2.3 Majsbort, 1967	3.8	7.3 Hauser & Kurland, 1975
60+	(n = 9)	1.2 Kurland, 1959	3.8	10.2 Hauser & Kurland, 1975
Male		50% deGraaf, 1974; Hauser & Kurland, 1975	54%	65% Kurland, 1959
Female		35%	46%	50%

areas of the body (Kiely and Lubin, 1983).

In reviewing the dozens of studies compiled by Kiely and Lubin (1983), no noteworthy age or sex specific patterns of occurrence can be found. However, we did find wide variation in age-specific prevalence rates from study to study. This can be attributed to sampling error, case finding differences, and possibly to actual differences in the prevalence of epilepsy in different geographic areas. Table 9 presents the range of age-specific prevalence rates found in the surveys and registries reviewed by Kiely and Lubin (1983).

3. Cerebral Palsy (Table 10)

Cerebral palsy is a chronic disorder of muscle control or coordination resulting from injury to the brain during fetal, perinatal or early childhood stages of development. Incidence is strongly associated with low birth weight, intra-uterine growth retardation and adverse prenatal factors. As Table 10 illustrates, there is a wide variation in the prevalence of cerebral palsy found in different areas probably due to incomplete case identification (e.g, Hansen, 1960), inconsistent case definitions and actual regional differences. U.S. rates appear higher than rates found in other countries; according to Kiely, Lubin and Kiely, (1984), this may be partly a function of more complete case identification procedures in the U.S studies and partly a function of etiologic differences such as low birthweight.

Most studies of the prevalence of cerebral palsy are limited to children. The highest rates appear to be among children five

TABLE 10

ESTIMATED PREVALENCE RATES (PER 1,000 GENERAL POPULATION) OF CEREBRAL PALSY, BY AGE AND SEX, BASED ON EPIDEMIOLOGIC SURVEYS AND REGISTRIES IN AREAS OUTSIDE IOWA

Age/sex	Number of sources	Low	Median	High
0 - 4 years	(n = 5)	1.5 CT State Dept. of Hlth.,1951	2.2	2.9 Wishik, 1956
5 - 9	(n = 5)	1.4 Hansen, 1960	2.3	8.8 Wishik, 1956
10 - 14	(n = 5)	1.3 Hansen, 1960	2.9	8.4 Wishik, 1956
15 - 19	(n = 5)	1.4 Hansen, 1960 (ages 15-18)	1.7	6.5 Wishik, 1956 (ages 15-20)
20 - 29	(n = 11)	-	1.1 Hansen, 1960 (one estimate)	-
20 - 49	(n = 1)	-	0.7 Gudmondsson, 1967	-
25 - 34	(n = 1)	-	0.8 Levin, 1949	-
35 +	(n = 1)	-	0.3 Levin, 1949	-
> 50	(n = 1)	-	0.2 Gudmondsson, 1967	-
Male	(n = 4)	53% Lagergren, 1970	57%	61%
Female	(n = 4)	39% Lagergren, 1970	44%	47%

to 14 years of age. The few studies done on adults show rates declining with age -- perhaps a function of age-specific mortality among adults with cerebral palsy. Most studies found a higher rate of prevalence among males than females. Only one study looked at the prevalence of cerebral palsy by race and found a higher prevalence among white children (Nelson and Ellenberg, 1978) -- a surprise given that low birth weight and perinatal mortality are higher among black neonates (Niswander and Gordon, 1972). Kiely, Lubin and Kiely (1984) could identify no clear secular trends in cerebral palsy -- trends that have been hypothesized by some researchers in light of recent advances in newborn intensive care.

4. Autism

Autism is a developmental disorder with severe distortions of social and language development that begin at an early age. According to the American Psychiatric Association, a child is diagnosed as having infantile autism only if all of the following features appear during the first 30 months of life (Schora, 1983):

- lack of responsiveness to other people;
- grossly impaired development of language;
- peculiar speech patterns, when speech is present, such as echolalia (repeating the speech of others); pronominal reversal (e.g., the use of "you" and "I"); or metaphorical language (e.g., the repetition of words or sound with unclear or "private" meanings);
- bizarre interactions with, or responses to, the environment, such as extreme fascination with unusual objects; resistance to even minor changes; and behavior rituals (often involving repetitive acts such as flicking the fingers) which, if interfered with, lead to great distress or tantrums;

- absence of hallucinations, delusions, and other features of schizophrenia.

Based on a review of five studies, Kiely and Lubin (1983) found the reported prevalence of rates of autism among persons below 19 years of age to vary from 0.21/1000 to 0.48/1000. They found approximately three times as many males as females with a diagnosis of autism.

5. Other Less-Prevalent Developmental Disabilities

Some of the less prevalent developmental disabilities are generally accompanied by mental retardation and thus are counted as part of the larger mental retardation population. These include bronchopulmonary dysplasia, stroke, severe cranio-facial disfigurement, deaf-blind, Huntington's disease, hereditary progressive muscular dystrophy, spina bifida, systemic Lupus-ery-themotosus and tuberus sclerosis (Gollay, 1981(2)). Reasonably reliable estimates of the age-specific prevalence of most of the less-prevalent developmentally disabling conditions are not available. They are too few in number to support the calculation of age-specific prevalence rates from completed surveys and registries.

The incidence of some of these conditions can be identified at birth. Still others can be identified in early infant monitoring and screening programs. However, while the duration and disabling effects of some of these conditions can be predicted, the duration and disabling effects cannot be predicted for most others. Consequently, it is not possible to derive reliable prevalence rates for most of these conditions,

particularly lifetime prevalence estimates (Gortmaker and Sappenfield, 1984).

6. Multi-Handicapped

Persons who have one developmental disability are likely to have others. Consequently, in order to obtain an unduplicated count or estimated prevalence of developmental disabilities, one cannot simply total the categorical prevalence estimates. One must first factor out the numbers of persons who have multiple disabling conditions.

The predominant area of overlap is between mental retardation and other developmental disabilities. Cerebral palsy, epilepsy and autism also co-occur (Pond, 1979; Hopkins, Bice and Colton, 1954; Jacobson and Janicki, 1983). In their analysis of approximately 50,000 persons in New York known to be receiving or known to need specialized interventions or developmental disabilities services during the period November 1978 through June 1982, Jacobson and Janicki (1983) found that persons with mental retardation accounted for 68% of instances of autism, 71% of instances of cerebral palsy, and 91% of instances of epilepsy. Thirty-five percent of adults (age 22 and above) and 25% of children (under age 22) with mental retardation also had epilepsy, cerebral palsy, and or autism.

Baird and Sadovnik, (1985) report even higher rates of multiple handicaps among severely and profoundly mentally retarded persons: from 71.7% to 91.6% of severely mentally retarded persons registered in the British Columbia Health Surviellance Registry from 1952 through 1966 had other disabling

conditions including cerebral palsy, epilepsy and autism. The proportion of retarded persons with multiple handicaps was found to increase dramatically with the degree of retardation. Fifty-six percent of children with profound mental retardation as opposed to 21% with mild mental retardation had multiple handicaps. Thirty-seven percent of adults with profound mental retardation as opposed to 25% of adults with mild mental retardation had multiple handicaps (Jacobson and Janicki, 1983).

Other researchers report generally lower estimates. For instance, the Oregon State Board of Health (1962) reports that 15.75% of severely mentally retarded children were found to have cerebral palsy and 17.27% had epilepsy. Drillien et al. (1966) found 22.94% of mentally retarded persons with cerebral palsy and 8.72% with epilepsy. Lindberg (1979) found that 21.3% of persons with mental retardation also had epilepsy and 4.7% also had cerebral palsy, and Pond (1979) found that 33% of severely mentally retarded persons had epilepsy and that three to six percent of mildly mentally retarded persons had epilepsy.

In estimating the prevalence of multi-handicapped persons as shown in Table 11A, HSRI assumed that Jacobson and Janicki's figures* (Table 11B) are an accurate reflection of the co-

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Note: Because Jacobson's and Janicki's figures represent persons served or awaiting developmental disabilities services in New York, and do not include developmentally disabled persons who have chosen not to enter or have previously exited the system (who as a general rule would probably be more capable and have a lower proportion of multiple handicaps), the figures probably represent a higher rate of co-occurrence than would be true were the population to include those unserved as well as those served or awaiting services.

TABLE 11A

ESTIMATED PREVALENCE RATES (PER 1,000 GENERAL POPULATION) OF PERSONS WITH SEVERE MENTAL RETARDATION, CEREBRAL PALSY, EPILEPSY, AUTISM, ALONE OR IN COMBINATION, BY AGE

Age	Severe mental retardation	Epilepsy	Cerebral palsy	Autism	Total	Multiply-handi-capped	Grand total
0 - 4 years	0.59	0.28	0.46	0.12	1.45	0.68	2.13
5 - 9	2.34	0.28	0.48	0.12	3.22	1.52	4.74
10 - 14	2.28	0.37	0.61	0.12	3.38	1.59	4.97
15 - 19	2.34	0.37	0.36	0.12	3.19	1.50	4.69
20 - 29	2.18	0.37	0.1	0.04	2.69	1.27	3.96
30 - 39	1.58	0.31	0.1	0.04	2.03	0.96	2.99
40 - 49	1.35	0.27	0.1	0.02	1.74	0.82	2.56
50 - 59	0.98	0.27	0.03	0.01	1.29	0.6	1.89
60 +	0.45	0.27	0.03	0.00	0.75	0.1	0.85

TABLE 11B

PERCENT OF CASES OF SELECTED DEVELOPMENTAL DISABILITIES OCCURRING ALONE OR IN SOME COMBINATION (MULTI-HANDICAPPED), BY TYPE OF DISABLING CONDITION AND AGE: NEW YORK STATE, 1978-1982

Disabling condition		Children (under age 21)	Adults (age 22 +)
a	Autism	65%	89%
b	Cerebral palsy	79%	86%
c	Epilepsy	92%	93%
d	Mental retardation	35%	25%
e	Multi-handicapped	47%	32%

Source: Jacobsen and Janicki (1983).

occurrence of mental retardation, cerebral palsy, epilepsy and autism generally. Accordingly, HSRI first reduced the generalized prevalence rates for mental retardation, epilepsy, cerebral palsy and autism presented earlier by the percentages shown in Table 11B (rows a through d) in order to arrive at the prevalence of cases of each condition alone. Then HSRI multiplied the sum of these prevalence rates by 47% in order to obtain the prevalence rates for multiply handicapped persons.

I. Validity and Reliability of these Estimates

1. Validity and Reliability

The validity (i.e., the extent to which prevalence estimates truly represent the prevalence of developmental disbilities) is largely a function of how developmental disabilities are defined. If the definitions are relatively loose, the prevalence estimates will be relatively high. If the definitions are relatively tight, the prevalence estimates will be relatively low.

As Kiely and Lubin (1983) explain, one of the reasons for the relatively wide variations in the reported prevalence rates is that different researchers employ different definitions. For instance, a study of the prevalence of mental retardation that focuses on individuals with I.Q.'s below 50 or includes measures of adaptive behavior will result in a prevalence rate that is considerably lower than a study that defines mental retardation solely on the basis of an I.Q. below 70.

The reliability of estimates of the prevalence of developmental disabilities is heavily a function of the size of

the survey sample upon which the prevalence estimates are based. To understand the role of sample size in the determination of reliability, the notion of "sampling error" must be addressed. Such error is the difference between the characteristics of a sample and the characteristics of the population from which the sample was drawn. This is because a particular sample used in a survey is one of a large number of possible samples of the same size that could have been selected using the sample design. Likewise, an estimate of some parameter (e.g., the number of persons having cerebral palsy) derived from a particular sample is one of many estimates that could have been derived from other possible samples from the same population. These estimates form a distribution that is centered around the true value for the given parameter. Most estimates, therefore, differ from the mean value of the estimate by some amount. The deviation of a sample estimate from the mean or average of all possible sample estimates is defined as the sampling error.

Sampling error is represented or measured by a statistic called the standard error. Hence, the standard error of an estimate is a measure of the precision with which an estimate from a sample measures the true value of the parameter, the true value being the mean of all possible sample estimates, assuming no unsuspected bias or nonsampling error. The precision of an estimate in turn is affected by the size of the sample from which the estimate is based. Specifically, the size of the standard error is inversely related to the square root of the size of the sample upon which an estimate is based.

Because the prevalence of developmental disabilities is relatively low, the size of the sample must be quite large in order to derive reasonably reliable estimates of the prevalence of most developmentally disabling conditions. This is particularly so in the case of those disabling conditions ocurring infrequently such as Tourette's syndrome, spina bifida and neurofibromotosis. For this reason, even the larger surveys must group such low incidence disabilities as "other."

As was seen in Table 3A the standard error of the estimates of the prevalence of developmental disabilities generated from even the largest surveys is too high to use these estimates unchecked. Standard errors of the prevalence estimates derived from many of the smaller area surveys done in other areas of the country and the world are relatively low when generalizing only to the areas studied. However, the inestimable error involved in assuming, as one must, that these area estimates can be generalized to Iowa and to its planning districts is probably equally as great as or greater than the sampling error indicated for the 1976 Survey of Income and Education. For these reasons, HSRI prepared estimates from a number of different sources.

2. Concurrent Validity

Table 12 juxtaposes prevalence rates for mental retardation and other developmental disabilities by age under the alternative methods of estimation (discussed previously). Table 12 facilitates the comparative analysis of these estimates. It allows for the assessment of the probable validity and reliability of these estimates according to their degree of

TABLE 12

ESTIMATED PREVALENCE RATES(PER 1000 GENERAL POPULATION) OF DEVELOPMENTAL DISABILITIES IN IOWA
USING DIFFERENT ESTIMATION METHODS

		1976 Survey of Income and Education (b)			1980 Census(c)		Epidemiologic studies:					Registries:	SSI/SSDI Records: Quadrant Method		
							Prevalence	Prevalence	Prevalence	Prevalence	Incidence/ Mortality	High-risk Infants			
Age (a)	Population	MR, severe	Other DD	All DD	MR, severe	Other DD	MR, severe/o	MR, mild	Other DD(e)	All DD	All DD	All DD	All MR	Other DD	All DD
Infants & pre-schoolers															
0 - 2	141,600										5.65	5.70			
3 - 5	138,480	2.60	3.50	6.10	0.05	0.10					10.20	10.00			
0 - 5	280,140						1.82	2.10	0.86	4.78					
School age															
6 - 17	513,000	5.10	14.80	19.90	0.60	1.10	4.17	4.79	1.46	10.42					
18 - 21	181,600	5.00	4.20	10.00	1.60	1.60	3.63	4.18	0.72	8.54					
6 - 21	694,600	5.28	12.03	17.31	0.86	1.23	4.03	4.63	1.27	9.93					
Adults															
22 - 64	1,517,660	1.50	0.40	1.90	1.10	0.40	2.20	2.53	0.30	5.03					
65 +	412,800	1.70	10.70 (d)	12.40	0.40	0.50	0.53	0.61	0.30	1.44					
22 +	1,930,460	1.54	2.60	4.15	0.95	0.42	1.84	2.12	0.30	4.26					
0 - 17	793,140												5.69	1.72	7.41
18 - 64	1,699,260												5.22	1.98	7.20

(a) Age divisions in the source data were interpolated when necessary to make the age divisions agree with the age divisions established for planning purposes.

(b) Civilian noninstitutionalized population only.

(c) Institutionalized population only. 1980 Census of Population: Persons in institutions and other group quarters.

(d) The SIE estimation method produces an artificially high estimate of the number of elderly persons who have developmental disabilities other than mental retardation.

(e) Based on unduplicated estimates shown in Table 11A.

NOTE: The mental retardation categories include all persons with mental retardation as a secondary and tertiary as well as a primary condition.

consistency.

The estimated prevalence of the developmentally disabled population ages five and under as estimated from the high risk infant registries is about the same as the prevalence estimates based on available epidemiologic data on the incidence and mortality associated with selected potentially disabling conditions and expert judgment on the probability of these conditions resulting in a disability. As earlier explained, both sources should be viewed as providing underestimates or at least conservative estimates of the true prevalence rates of developmental disabilities among this age group, though not nearly as conservative as estimates based on epidemiologic studies, which commonly under-identify disabled infants and toddlers.

Officials responsible for these registries invariably report that the registries are incomplete; their systems have not yet developed to the point of 100% participation. Also many disabilities are simply not readily detected and diagnosed until a child begins school. Indeed some states, Iowa included, postpone formal diagnoses until children reach age three. Similarly leading to the under identification of disabled children from birth defects registries is the inability to gain the full cooperation of physicians and nurses who must identify and report these cases.

The prevalence rates for mental retardation as estimated from the 1976 Survey of Income and Education (SIE) are confined to the noninstitutionalized population; the prevalence rates as

estimated from the 1980 Census of Population (COP); Persons in Institutions and Other Group Quarters are confined to the institutionalized population. Accordingly, these two sets of rates should be considered in combination. The rates of severe mental retardation among school age children are as estimated from the SIE/COP, about 20% higher than the rates of severe mental retardation as estimated from the epidemiologic studies, and about the same as the rates for all mental retardation as estimated using the Quadrant Method. The difference may lie in the fact that the epidemiologic estimates are based on IQ or learning potential; the SIE/COP and Quadrant estimates are based on level-of-functioning criteria.

SIE estimates of the prevalence of persons with developmental disabilities other than mental retardation among the general population ages 6-17 are judged to be artifically high. This is because the "activity limitation" criteria are not sufficient to screen out some of the less severely disabled children. Conversely, the epidemiologic estimates of other developmental disabilities are relatively low as they include only epilepsy, cerebral palsy, autism; they do not include other nervous, physical, sensory and other impairments.

The Quadrant Method is judged to provide the most reliable estimates of developmental disabilities among the population one to 17 in Iowa and of the prevalence of the developmentally disabled population with mental retardation in the general population ages 18-64. This is for two reasons:

1) the methods (the ICAP employed in the enumeration study and the eligibility determination procedures in the SSI

and SSDI programs) used to identify developmentally disabled persons with mental retardation and other developmental disabilities are more thorough and exacting than is true in the case of the other estimation methods.

2) The number of cases upon which the Quadrant Method estimates are built is larger than the number of cases upon which the SIE survey estimates are built, and unlike the epidemiologic-based estimates, these cases are Iowa-specific. Thus the sampling error should be lower.

With respect to the prevalence of developmental disabilities among the general population ages 65 and over, the 1976 Survey of Income and Education-based prevalence rates (noninstitutionalized population) together with the 1980 Census of Persons in Institutions and Other Group Quarters (institutionalized population) are judged to provide the best available basis for estimating the prevalence of mental retardation in the elderly population age 65 and over.

No reliable sources of information on the prevalence of developmental disabilities other than mental retardation could be found for the adult population. This is because available figures on the prevalence of disabilities other than mental retardation do not distinguish those persons whose disabilities began prior to the age of 22 and thus who by definition are developmental disabilities. While one might reasonably assume that all mentally retarded adults have been so since childhood and thus are developmentally disabled, the same assumption cannot be made for adults with other disabilities.

3. Estimation Bases

Based on these and lesser considerations, in estimating the size of the MR/DD population in Iowa, statewide and by planning

district, HSRI used:

- o the Quadrant Method to estimate the size of the entire developmentally disabled population age 17 and under and the size of the mentally retarded population ages 18-64; and
- o the 1976 Survey of Income and Education and 1980 Census of Persons in Institutions and Other Group Quarters to estimate the size of the mentally retarded population age 65 and above.

In the absence of figures on the prevalence of developmental disabilities other than mental retardation among the general population ages 18 and above, HSRI made the assumption that "the prevalence rate of other developmental disabilities relative to the prevalence rate of mental retardation remains relatively constant across age groups. Specifically, HSRI assumed that the prevalence of developmental disabilities other than mental retardation in the age groups 18 to 64 and 65 and above is equal to HSRIs estimates of the number of children on the SSI rolls for reason of mental retardation in Iowa plus the number of adults awarded SSDI benefits for reason of mental retardation observed prior to age 18 divided by the number of children on the SSI rolls for reasons of other developmental disabilities (not including mental illness) plus the number of SSDI beneficiaries receiving SSDI benefits for reason of other disabilities occurring prior to age 18. These estimates are presented in Table 5.

J. Developmental Disabilities Population Trends

As noted earlier, though mental retardation, cerebral palsy and epilepsy by no means constitute the entire developmentally disabled population, they do represent the most common

developmental disabilities, certainly in terms of persons coming to demand publicly-supported services. In Iowa, as in most states, the great majority of persons receiving publicly-funded services have some degree of mental retardation.

Therefore in projecting changes in the potential demand for residential and related support services in Iowa, the most significant segment of potential demand is expceted to come from those with mental retardation and associated handicaps of biologic origin, 90% of which are manifest at birth or early infancy (Grossman, 1983). The causal factors include infectious disease, genetic disease, birth complications associated with low birth weight, and other biomedical causes. Some of the factors are on the increase, some on the decrease, but the incidence of most appears relatively steady (Birth Defects Monitoring System, unpublished data, 1981).

According to unpublished statistics compiled as part of the Birth Defects Monitoring Program, there has been little significant change in the incidence of mental retardation-associated birth defects over the past decade. At the same time, the incidence of total congenital anomalies (nervous system) has declined very slightly. The incidence of Down's Syndrome appears relatively steady; the effects of advances in prenatal diagnostic capabilities are likely being offset by increases in maternal age and improved intensive neonatal care. Exceptions are the incidence of anencephaly (brain defects) and spina bifida, which have declined about 40% from 1970-73 to 1984. The incidence of congenital rubella has also declined dramatically and the

incidence of hemolytic newborn disease has been halved during this period. In contrast, the incidence of hip dislocations with central nervous system defects has increased threefold, and the recognized incidence of autosomal abnormalities (excluding Down's Syndrome) has doubled (though this may be a function of increased recognition rather than increased incidence).

There has been only a slight decline in the prevalence of premature births and low-weight births (under 1,500 grams) over the past decade. In past years, low birth weight infants accounted for a substantial proportion of all developmental handicaps. In the 1950s and early 1960s infants weighing less than 2000 grams accounted for about 10-15% of all severe mental retardation (Drillien, 1968; Birch et al., 1970; Gustavson et al., 1977) and about 30-40% of all cerebral palsy (Lillenfield and Parkhurst, 1951; Childs and Evans, 1954; Eastman and DeLeon, 1955; Foster, Guy and Perry-Jones, 1956; Fuldner, 1957). The risk of cerebral palsy was 6.5% in McDonald's survey of infants under 1800 grams (McDonald, 1967), and 9% in the Collaborative Perinatal Project's survey of infants under 1500 grams (Ellenberg and Nelson, 1979).

However, while the incidence of premature and low-weight births and of most biological factors associated with mental retardation and associated nervous system disorders have remained relatively steady, survival rates continue to increase. Philip, et al. (1981) estimate, based on a survey of neonatal care centers throughout England and North America, that the neonatal survival of infants weighing less than 1500 grams at birth has

increased from about 38% in the 1960s to 51% in the 1970s to about 69% in the late 1970s (Gortmaker and Sappenfield, 1984). Elwood and Elwood (1980) report an increase in the survival of children with spina bifida from four to eight years owing to advances in surgical treatment. As Grossman (1983) observes "much progress has been made during the past two decades in developing facilities and treatment for the intensive care of such high-risk infants. Biochemical abnormalities such as hypoglycemia and hypoxia can now be diagnosed readily and treated effectively. Respiratory distress and anoxia, once major causes of brain damage, are now also subject to treatment without consequent morbidity in most cases."

What is unknown is the net affect of these advances on the prevalence of neurologic impairments. According to reports by Shapiro, McCormack and Stanfield (1983), and Hack, Faranoff and Merkatz (1979), overall rates of severe impairment among surviving low birthweight infants currently appear to be less than 20% (Gortmaker and Sappenfield, 1984). While some suspect that these advances are leading to decreases in the prevalence of neurologic impairments (Gortmaker and Sappenfield, 1984; Grossman, 1983), others (Drillien, 1958; Hold, 1970) suspect that an increased number of handicapped children are surviving. Still others (Kiely, Paneth and Susser, 1981) are uncertain.

The positive advances in stemming the prevalence of lead encephaly (mostly among low income children) are being offset to some degree by increases in the incidence of other acquired postnatal factors such as bacterial meningitis (Underman,

Overturf, Leedmon, 1978).

There is increasing evidence that the extent to which mental retardation and associated neurologic impairments of biologic origin result in adaptive skill deficits and maladaptive behaviors is heavily influenced by biosocial and psychosocial factors. Children in supportive and stimulating environments appear to be able to compensate for the biologic defects to a greater extent than children not having such benefits. The beneficial effects of early intervention programs are well documented.

However, the positive effects of early intervention programs notwithstanding, considering the relative stability of most biologic factors leading to mental retardation and associated neurologic impairments, and the unsettled question of the increased survival of low birthweight infants on the prevalence of mental retardation and neurologic impairments, the most reasonable assumption for planning purposes is that the prevalence of moderate, severe and profound mental retardation and other developmental disabilities will continue at the same rate over the next five to ten years. This assumption is reflected in HSRI's projections of the size of the developmentally disabled population (potential demand) in Iowa statewide and by district in the years 1990 and 1995 (see Tables 1B, 1C and 2B and 2C).

TABLE 13

IOWA POPULATION PROJECTIONS BY DISTRICT

1985

AGE	STATE	DISTRICT: 1	2	3	4	5	6	7	8
ALL	2,905,400	309,155	259,953	323,995	412,439	430,365	549,686	338,437	280,369
0-17	793,140	87,222	69,393	91,444	120,978	114,015	145,930	92,604	71,554
18-64	1,699,260	175,130	146,991	189,542	247,354	266,187	344,305	191,298	138,453
65+	412,300	46,554	43,088	43,181	45,055	51,424	60,791	54,047	68,659

1990

AGE	STATE	DISTRICT: 1	2	3	4	5	6	7	8
ALL	2,913,500	311,703	258,317	324,524	421,079	445,118	560,504	341,050	251,205
0-17	799,540	89,525	69,321	91,988	121,683	114,074	147,394	94,151	70,903
18-64	1,686,360	170,652	141,150	184,730	249,249	273,215	344,733	188,080	134,552
65+	427,600	51,492	47,799	47,799	50,194	57,878	67,957	58,776	45,704

1995

AGE	STATE	DISTRICT: 1	2	3	4	5	6	7	8
ALL	2,931,300	313,457	256,154	327,029	431,180	438,317	571,119	344,220	250,323
0-17	801,400	89,389	68,156	92,328	123,017	114,840	148,488	94,987	70,195
18-64	1,696,800	171,706	140,065	187,002	256,318	264,067	352,291	189,367	135,484
65+	433,600	52,284	47,877	47,677	51,384	59,496	70,514	59,296	44,572

APPENDIX A

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APPENDIX B

CRITERIA EMPLOYED IN IDENTIFYING RESPONDENTS TO THE 1976 SURVEY OF INCOME AND EDUCATION AS DEVELOPMENTALLY DISABLED

CHART II

LIFE ACTIVITY LIMITATIONS - SIE OPERATIONAL DEFINITIONS

1. SELF-CARE

Age Group	Question	Response
5-13	Q 91 (personal needs)	Usually/Frequently Needs Help
14-	Q 68 (personal needs)	Usually/Frequently Needs Help

2. RECEPTIVE AND EXPRESSIVE LANGUAGE

Age Group	Question	Response
5-13	Q 91 } Limiting Health Condition	Mental Retardation Hard of Hearing Deaf Speech Impairment Serious Difficulty Seeing or Blind
14-	Q 70 } Limiting Health Condition	

PLUS ONE OF

5-13	Q 88 (regular school work)	Yes, Having Difficulty
14-17	Q 60 (regular school work)	Yes, Having Difficulty
18-21	Q 63A (regular school work)	Yes, Having Difficulty
18-	Q 24 (highest grade attended)	3 (Third)

3. LEARNING

Age Group	Question	Response
5-13	Q 91 } Limiting Health Condition	Mental Retardation Deaf Serious Difficulty Seeing or Blind Seriously Emotionally Disturbed 2+ Other Limiting Health Conditions
14-	Q 70 } Limiting Health Condition	

4. MOBILITY

Age Group	Question	Response
3-4	Q 87 (play)	Yes, Limited in Ability

Age Group	Question	Response
5-13	Q 92 (get around outside)	Usually/Frequently Needs Help
14-	Q 69 (get around outside)	Usually/Frequently Needs Help

5. SELF-DIRECTION

Age Group	Question	Response
5-13	Q 93 } Limiting Health	Mental Retardation
14-	Q 70 } Condition	Seriously Emotionally Disturbed

6. CAPACITY FOR INDEPENDENT LIVING

Serious Difficulty in Self-Direction

OR

Age Group	Question	Response
5-13	Q 88A (school attendance)	Cannot Attend or Frequently Absent
	PLUS EITHER	
	Q 91 (personal needs)	Usually/Frequently Needs Help
	Q 92 (get around outside)	Usually/Frequently Needs Help
14-17	Q 60A (school attendance)	Cannot Attend or Frequently Absent
	PLUS EITHER	
	Q 68 (personal needs)	Usually/Frequently Needs Help
	Q 69 (get around outside)	Usually/Frequently Needs Help
18-19	Q 61B (school attendance)	Cannot Attend or Frequently Absent

Age Group	Question	Response
	OR	
	Q 66 (work)	Cannot Work At All
	OR	
	Q 66A (work)	Can Work Only Occasionally/ Irregularly
	PLUS ONE OF	
	Q 67 (work around house)	Limited in Amount or Kind
	Q 68 (personal needs)	Usually/Frequently Needs Help
	Q 69 (get around outside)	Usually/Frequently Needs Help
24-64	Q 66 (work)	Cannot Work At All
	OR	
	Q 66A (work)	Can Work Only Occasionally/ Irregularly
	PLUS ONE OF	
	Q 67 (work around house)	Limited in Amount or Kind
	Q 68 (personal needs)	Usually/Frequently Needs Help
	Q 69 (get around outside)	Usually/Frequently Needs Help
65-	Q 67 (work around house)	Limited in Amount or Kind
	PLUS EITHER	
	Q 68 (personal needs)	Usually/Frequently Needs Help
	Q 69 (get around outside)	Usually/Frequently Needs Help

7. ECONOMIC SELF-SUFFICIENCY

Age Group	Question	Response
18-44	Q 66 (work)	Cannot Work At All
	Q 58 (school enrollment)	Not Enrolled
	AND	
	Q 66A (work)	Limited In Amount Or Kind, But Can Work Occasionally/ Irregularly Or Regularly
	PLUS EITHER	
	Q 14F (work history)	Never Worked Fulltime 2- Weeks Or Never Worked At All
	Q 16 (work history)	Never Worked At Regular Job For Pay
	Q 66A (work)	Limited In Amount Or Kind, But Can Work Occasionally/ Irregularly Or Regularly
	PLUS EITHER	
	Q 46A (welfare)	Receives Public Welfare
	Q 46D (public compensation)	Receives Workmen's Compensation
	Q 58 (school enrollment)	Not Enrolled
	AND	
	Q 66A (work)	Limited In Amount Or Kind, But Can Work Occasionally/ Irregularly Or Regularly
	AND	
	Q 24 (highest grade attended)	7 (Seventh)
	Q 58 (school enrollment)	Not Enrolled

CHART II (continued)

Age Group	Question	Response
		AND
	Q 66A (work)	Limited In Amount Or Kind, But Can Work Occasionally/ Irregularly Or Regularly
		AND
	Earned Income (calculated)	$5,000.00
	Q 45B (SSI)	Receives U.S., State or Local

APPENDIX C

PROCEDURE USED TO ESTIMATE THE NUMBER OF DISABLED CHILDREN AND ADULTS ON THE SSI AND SSDI ROLLS

An updated census of the number of adults on the SSI and SSDI rolls is available for the end of each calendar quarter. However, these counts are not broken out by disabling condition.

Figures are available on the number of SSI and SSDI awards each year by disabling condition in the United States from 1955 through 1973 and from 1975 to date. The Social Security Administration will not release the 1974 data as it is considered to be unreliable. Like data is also available by state though the disabling conditions are grouped (e.g., mental illnesses are shown together with mental retardation under the group entitled mental disorders). These data are available for fewer years.

HSRI might have estimated the number of adults on the SSI or SSDI rolls by type of disabling condition (e.g., mental retardation) by simply assuming that the proportion of persons on the disability rolls for reason of mental retardation at any given point in time is the same as the proportion of total awards made for reason of mental retardation in years past. This assumption would be valid if persons with different types of disabling conditions remain on the rolls for the same period of time. However, available data indicate otherwise. According to Goff (1971), Cormier (1971), and Treitel (1979), persons awarded SSDI benefits for reason of mental disorders are likely to continue on the rolls for a longer period of time than are persons awarded benefits for other reasons. In view of these findings, it's apparent that the use of such a simplifying assumptions would lead to under-estimates of the size of the developmentally disabled population actually on the rolls, at

least insofar as the mentally retarded segment of the population is concerned.

Accordingly, in place of this assumption HSRI estimates the numbers of persons on the SSI and SSDI rolls for reason of mental retardation and other disabilities each year from 1955-1984 by their expected duration on the rolls.* Data on the average duration of SSI and SSDI cases by type of disabling condition were compiled from regularly scheduled disability reviews and continuing disability investigations conducted by the Social Security Administration in the years 1981 through 1983; the average duration statistics on SSI cases, from an internal study of a cohort of SSI awardees from 1977 through 1981 (Kochhar, 1985). The selection criteria for cases to review and for inclusion in Kochhar's study were not found to be biased in terms of the variables of interest: specifically, duration on the rolls and recipient age within particular disability groups (Krute, 1985).

Using these data HSRI constructed tables showing the probability of SSDI and SSI awardees in each of the years 1955-1984 remaining on the rolls at the end of the year of award and subsequent years through 1984 by category of disabling condition. Individual tables were constructed for two of the three types of SSDI beneficiaries, namely (1) workers and (2)

* These categories of disability are: Infectious and parasitic diseases; neoplasms; Endocrine; Nutritional, and Metabolic disorders; blood and blood forming disorders, mental illness, mental retardation, nervous system and sensory disorders, circulatory disorders, respiratory disorders, digestive system disorders, musco-skeletal impairments, and other.

children (age 18 and above dependent on an insured worker). A table for disabled widows of SSDI workers was not compiled as these cases were too few in number to derive reasonably reliable estimates and to be of any significance. "Life" tables were also constructed for SSI adult and SSI child recipients for reason of disability using data on the current payment status of a cohort of individuals awarded payments for reason of disability in 1977 (Kochhar, undated).

Using these "lifetables" HSRI is able to estimate the numbers of each type of SSI and SSDI awardee in a given state each year (from 1955 through 1984) expected to still be on the rolls as of December 31, 1984 by disability group. The total number in each disability group expected to still be on the rolls as of December 31, 1984 is obtained by summing these estimates across all years (1955 through 1984).

Comparing the grand total of the numbers in each disability group estimated to be on the rolls as of December 31, 1984 according to the Quadrant method against the known counts of all SSDI and all SSI disability cases as of December 31, 1984 in the state serves to check the relative accuracy of the estimates. The estimated totals by disability group are then corrected to the known SSI and SSDI totals adjusting them by the percentage difference between the estimated SSI and SSDI totals and known SSI and SSDI totals.

Sources of Error

Logically speaking these estimates of the number of adults on the SSI and SSDI rolls by disability group, because they are

sensitive to differences in the length of time SSI payees and SSDI beneficiaries remain on the rolls, should be more accurate than estimates not sensitive to these differences. However, the relative accuracy of these estimates cannot be represented statistically as the estimates are based on assumption as well as hard data. Assumptions were necessary to impute values for missing data. State-by-state figures were missing on the number of awards by disability group:

- o for SSDI worker awardees in years 1955 through 1965, and 1984.
- o for SSDI childhood awardees* in years 1974 through 1984
- o for SSI awardees in years 1955-1974 and 1977-1984**

Prior to 1974, disability awards to indigent persons were made as part of the state welfare programs and not as part of the federal SSI program. Knowing the total number of persons in the United States and by State on the SSI rolls in 1975 and having estimates of the numbers of persons in the United States on the rolls by disability group in 1970, it was possible to use the SSI life tables to estimate the breakout of disability cases on the rolls as of December of 1975 by disability group by state assuming that the size and proportion of disability cases by state in 1970 mirrored that known in 1975. The life tables would

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* Counted as SSDI childhood awardees are disabled persons age 18 and over whose disability began before age 22 (age 18 before January 1973); these persons were eligible to receive benefits beginning in 1957.

** Within two years the Social Security Administration expects to maintain current estimates of the numbers of persons on the SSI rolls by disability group.

then apply to these 1975 base line figures and to the subsequent award cohorts. What little relevant data is available indicates that at least at the national level the proportion of cases by disability group remained relatively constant from 1970 through 1975 and thus this assumption has some foundation (Kocchhar, 1975).

The number of awardees in each disability group was imputed for those years where figures were missing by multiplying the known total number of awardees in the state that year by the average percent of awards made to that disability group in the years for which the data was available. In those cases where the average percent figures were markedly different in years closer to the year for which the data was missing than years distant, the average was taken on the closest years.

Data on the average length of time on the rolls by the different types of disabled beneficiaries (e.g., SSDI workers and SSDI children) was available at the national level for years one through 26. Data on the average length of time on the rolls for years 27 through 30 were projected using a linear regression technique following a logarithmic transformation of the data. The transformation was necessary in order to capture the curvilinear pattern of the data.

The same data was available on SSI adults and children combined. However the data available from Kochhars' study (1977 through 1981) was the data of choice as it separates adults from children and proved to be the more accurate predictor of state disability caseloads as of December 1984.

State-specific data was not available on the breakdown of SSDI and SSI awardees within the mental disorders (MD) group, specifically mental retardation (MR) as opposed to mental illness (MI). Therefore the state MR/DD breakdown within each disability group (i.e., SSDI workers, SSDI children, SSI adults, and SSI children).

Some disabled adults are on both the SSI and SSDI rolls. In order not to double count these individuals, their number has to be estimated and subtracted from HSRI's initial SSI or SSDI estimates. National statistics for March, 1980 show that 7.2% of adult blind and disabled workers were in concurrent receipt of SSI payments, and that 33.1% of disabled children (ages 18 and above and dependent on an insured worker) were in concurrent receipt of SSI payments. Unless state-specific estimates are available from state surveys or data bases HSRI uses these figures to reduce its national and state estimates of the numbers of adults on the SSDI and SSI rolls for reasons of mental retardation in order to arrive at an unduplicated estimate (Social Security Administration, unpublished data, March, 1980).

Table C.1. shows HSRI's estimated caseloads (using the Quadrant Method) as of December 1984 and caseloads as reported by states for which data was gathered as part of this and related HSRI projects. The SSDI estimation formulas for adult workers at the national level are 4.8% above the actual roll count; however the formulas uniformly underestimate the number of persons on the rolls in the 21 states by an average of 19.8%. The largest underestimate is for Florida, 50.9%, and the smallest, for Alaska

1.2%. At this time, HSRI cannot explain the consistent underestimation; however, the Institute is continuing to investigate possible reasons.

HSRI could obtain no reliable estimates of the number of childhood beneficiaries on the rolls as a check on HSRI's estimates.

HSRI formulas also result in underestimates of the SSI adult caseloads by 25.7% at the national level, and by 18.6% in the 21 states. In contrast, the formulas overestimate the number of children receiving SSI by 14.4% nationally, and by an average of 20.1% in the 21 states. The major reason for the consistent underestimates of SSI adults and partially offsetting overestimates of SSI children is that while those children ages 18-21 not in school are counted as adults by the Social Security Administration, those attending school continue to be counted as children.

TABLE C.1.

NUMBER OF PERSONS ON THE SUPPLEMENTAL SECURITY INCOME(SSI) AND SOCIAL SECURITY DISABILITY INSURANCE(SSDI) ROLLS
BY TYPE OF BENEFICIARY AND CATEGORY OF DISABILITY, AS ESTIMATED UNDER THE QUADRANT(Q) METHOD AND AS CORRECTED TO COUNT(C) AS OF DECEMBER, 1984:
UNITED STATES AND TWENTY-ONE STATES

STATE		SSDI ADULT				SSDI CHILD				SSI ADULT				SSI CHILD				PERCENT DIFFERENCE BETWEEN QUADRANT ESTIMATES & ROLL COUNTS			
	BASIS	TOTAL	MI	NR	OTHER	TOTAL	MI	NR	OTHER	TOTAL	MI	NR	OTHER	TOTAL	MI	NR	OTHER	ALL	SSDI ADULT	SSI ADULT	SSI CHILD
U.S.	Q	2729485	409898	63603	2254984	489606	28499	365227	95880	1923857	354718	432013	1137126	290515	31508	155432	103575	-6.5%	4.8%	-25.7%	14.4%
	C	2596535	390076	60527	2145932					2410522	445924	543093	1429505	248633	26966	133026	88643				
1. ALA	Q	42441	5383	153	36905	3998	89	1247	2662	43206	6607	8266	28253	8720	374	5107	3239	-29.5%	-34.3%	-35.4%	23.4%
	C	57013	7321	205	49487					58503	9087	11244	38172	6683	287	3914	2482				
2. AK	Q	1844	202	12	1630	98	3	35	60	1805	240	284	1281	308	15	203	90	-2.6%	-1.2%	-9.0%	26.6%
	C	1867	205	12	1650					1967	262	310	1395	226	11	149	66				
3. AZ	Q	22505	3051	101	19273	3204	163	2255	786	15158	2600	3176	9382	3019	117	1550	1352	-33.3%	-47.7%	-22.2%	18.6%
	C	33243	4507	268	28468					18522	3275	3881	11366	2457	95	1262	1100				
5. CA	Q	201216	34797	2142	164277	35040	1878	25856	7306	248398	45081	59376	143941	29419	1256	17868	10295	-34.5%	-21.4%	-31.4%	18.3%
	C	244272	42243	2600	199429					376158	68266	89913	217971	24026	1025	14592	8409				
6. CO	Q	20083	2873	176	17034	1194	26	360	808	15607	3576	4402	7629	2945	147	1956	842	-10.9%	-18.4%	-7.2%	21.1%
	C	23777	3402	209	20166					16735	3834	4720	8181	2325	116	1544	665				
8. DE	Q	5946	970	57	4919	1061	59	807	195	4112	906	1070	2136	810	37	503	270	-13.3%	-20.9%	-8.3%	17.0%
	C	7191	1174	69	5948					4455	982	1159	2314	672	31	417	224				
10. FL	Q	89132	11974	730	76428	12731	667	9117	2947	69986	11234	13395	45357	11140	496	6845	3799	-36.8%	-50.9%	-26.4%	11.3%
	C	134480	18066	1101	115313					88475	14201	16934	57340	9879	439	6070	3370				
11. GA	Q	62039	10524	638	50877	13339	711	9802	2826	62778	11263	14009	37506	10298	465	6598	3235	-24.4%	-27.0%	-29.6%	22.9%
	C	78817	13378	810	64637					81363	14598	18156	48609	7940	358	5087	2495				
16. IA	Q	23066	4246	260	18560	7204	403	5666	1135	14992	3917	4480	6595	3527	190	2636	701	-3.6%	-11.3%	0.6%	20.7%
	C	25672	4725	289	20658					14900	3893	4453	6554	2515	136	1880	499				
19. LA	Q	38987	4582	288	34117	11592	617	8517	2458	46561	8632	11296	26633	13656	664	9459	3533	-25.2%	-30.8%	-35.1%	24.6%
	C	50989	5993	377	44619					62087	11659	15527	35701	10298	501	7133	2664				
24. MN	Q	23712	4002	289	18621	7976	446	6190	1340	18358	4300	5295	8763	2773	147	1980	646	-14.4%	-27.5%	-1.9%	15.1%
	C	30234	6141	370	23723					18702	4381	5394	8927	2354	124	1681	549				
26. MO	Q	51145	7644	474	43027	12511	676	9326	2509	37969	7634	9276	21059	5948	299	4078	1571	-15.1%	-19.7%	-14.8%	23.8%
	C	61213	9148	568	51497					43683	8767	10653	24183	4577	230	3138	1209				
28. MS	Q	11981	1948	119	9834	3215	166	2396	653	7749	1503	1824	4422	1461	66	883	512	-3.3%	-5.2%	-4.5%	19.1%
	C	12523	2050	125	10348					8078	1570	1906	4622	1182	53	714	415				
30. NH	Q	11160	1894	112	9154	1784	108	1432	244	3611	946	1036	1629	508	21	293	274	15.0%	19.2%	1.7%	16.5%
	C	9021	1531	90	7400					3548	939	1028	1581	491	18	245	228				
31. NJ	Q	75001	11060	690	63251	12085	714	10094	1277	47637	10545	12421	24671	8752	389	5316	3047	-5.3%	-5.2%	-10.4%	21.6%
	C	78890	11647	727	66516					52572	11638	13707	27227	6862	305	4168	2389				
32. NM	Q	9326	1137	71	8118	824	18	240	566	10037	1783	2328	6726	2142	86	1182	874	-37.8%	-45.8%	-43.4%	25.6%
	C	13598	1659	104	11835					15545	2393	3125	10027	1594	64	879	651				
33. NY	Q	175832	26910	1679	147243	46202	2584	35937	7681	160218	27575	36559	96084	27791	1175	16485	10131	-17.6%	-11.6%	-29.3%	12.0%
	C	196267	30038	1875	164354					207084	35641	47253	124190	24460	1034	14509	8917				
38. OR	Q	23258	2399	151	20708	5252	280	3827	1145	13626	2051	2493	9082	2753	114	1561	1078	-12.7%	-16.7%	-12.5%	20.3%
	C	27134	2799	176	24159					15335	2309	2806	10220	2193	91	1243	859				
40. RI	Q	10565	1805	110	8650	1899	107	1478	314	6966	1298	1641	4027	1216	46	650	520	-23.5%	-24.4%	-29.1%	17.2%
	C	13146	2245	137	10764					8994	1676	2119	5199	1007	38	538	431				
41. VA	Q	48710	7143	435	41132	11834	646	9057	2131	37340	6441	7630	23269	5572	253	3501	1818	-24.6%	-28.9%	-25.3%	17.8%
	C	62765	9204	561	53000					46785	8070	9559	29156	4579	208	2877	1494				
42. WY	Q	2514	291	18	2205	694	38	516	140	1262	261	307	694	204	7	99	98	-1.5%	-9.8%	10.5%	27.9%
	C	2761	320	20	2421					1130	234	275	621	147	5	71	71				
														UNWEIGHTED AVERAGE: 21 STATES)				-16.4%	-19.8%	-18.6%	20.1%

APPENDIX D

WAITING LIST DATA FROM THE
UNIVERSITY AFFILIATED FACILITY'S
DEVELOPMENTAL DISABILITIES UPDATE QUESTIONNAIRE

PROVIDER	SERVICE	TOTAL	Ext Urge	Urgent	Some Urge	No Urge	Unk
ROOM AND BOARD							
1814	A	2	0	0	2	0	0
Percent by Urgency			0	0	100	0	0
SUPERVISED APARTMENT (WITH VISITING COUNSELOR)							
208	B	2			2		
1938	B	104				104	
1889	B	18	4	14			
1761	B	7			7		
1761	B	4				4	
1533	B	12		1	5	4	2
994	B	1		1			
458	B	1				1	
441	B	1			1		
431	B	1			1		
406	B	6				6	
380	B	4			4		
		161	4	16	20	119	2
Percent by Urgency			2.48	9.94	12.42	73.91	1.24
SUPERVISED APARTMENT (WITH LINE-IN COUNSELOR)							
208	C	4			2	2	
1889	C	15		3	12		
1848	C	68					68
994	C	21	6	2		13	
469	C	3			3		
421	C	2			2		
365	C	41					41
253	C	10		5	5		
1894	C	12			12		
318	C	2			1	1	
		178	6	10	37	16	109
Percent by Urgency			3.37	5.62	20.79	8.99	61.24
FOSTER CARE GROUP HOME (CHILDREN)							
2023	D	4		4			
1785	D	19		2			17
1430	D	30			30		
330	D	2			2		
		55	0	6	32	0	17
Percent by Urgency			0	10.91	58.18	0	30.91
COMMUNITY RESIDENTIAL FACILITY (CHILDREN)							
1761	E	2			1	1	
994	E	32	7	14		11	
445	E	10			2	8	
380	E	3			3		

PROVIDER	SERVICE	TOTAL	Ext Urge	Urgent	Some Urge	No Urge	Unk
253	E	6	2	4			
		53	9	18	6	20	0
Percent by Urgency			16.98	33.96	11.32	37.74	0
COMPREHENSIVE RESIDENTIAL FACILITY (CHILDREN)							
1761	F	2			2		
1297	F	23		20	1	2	
445	F	7			7		
352	F	2			2		
211	F	16		7	7	2	
169	F	16		1	7		8
1983	F	5			1	4	
		71	0	28	27	8	8
Percent by Urgency			0	39.44	38.03	11.27	11.27
RESIDENTIAL CARE FACILITY (INCLUDING CCFs)							
2064	G	1				1	
2021	G	3					3
1970	G	2				2	
1938	G	9				9	
1931	G	20	2	5	9	4	
1928	G	1				1	
1926	G	2					2
1925	G	10	1	5	4		
452	G	3			2	1	
441	G	1			1		
421	G	4			4		
412	G	10	2	7	1		
446	G	2				2	
400	G	5		1	4		
351	G	4					4
326	G	20	5	10	5		
324	G	11	2	6	3		
295	G	5				5	
224	G	7		1			6
190	G	2			2		
183	G	2			2		
1968	G	19		8	7	4	
442	G	3				3	
		146	12	43	44	32	15
Percent by Urgency			8.22	29.45	30.14	21.92	10.27
RESIDENTIAL CARE FACILITY/MENTAL RETARDATION							
2072	M	27			23	4	
1889	M	40		3	33		4
1865	M	14			14		
1861	M	7		3	4		
1847	M	3			3		
1759	M	3				3	
1655	M	11		3		8	

PROVIDER	SERVICE	TOTAL	Ext Urge	Urgent	Some Urge	No Urge	Unk
1297	H	20			8	12	
1295	H	1			1		
1010	H	2			1	1	
994	H	1				1	
483	H	6				6	
469	H	14		1	8	5	
468	H	4			4		
445	H	15		10	5		
431	H	7			5	2	
421	H	6		2	2		2
380	H	12		6	6		
364	H	4			4		
352	H	5		1	4		
321	H	7		4	3		
293	H	3			2	1	
276	H	33		4	15	14	
253	H	21	10	11			
237	H	6			3	3	
1894	H	13	1		12		
1867	H	160			10	120	30
318	H	15		10	3	2	
167	H	24			2	22	
166	H	2			2		
148	H	13		3	3	3	4
197	H	6			6		
165	H	8		2	6		
2047	H	3		1	2		
1864	H	7		3	4		
		523	11	67	198	207	40
Percent by Urgency			2.10	12.81	37.86	39.58	7.65
INTERMEDIATE CARE FACILITY (NURSING HOME)							
1938	I	1					1
1914	I	40	1	3	6	10	20
471	I	9	1	6	2		
323	I	2			2		
2063	I	30			10	20	
		82	2	9	20	30	21
Percent by Urgency			2.44	10.98	24.39	36.59	25.61
INTERMEDIATE CARE FACILITY/MENTAL RETARDATION							
204	J	27	0	3	4	10	10
2072	J	44			13	31	
1785	J	41				41	
323	J	26			6	20	
281	J	2				2	
265	J	8	1	3	2	2	
152	J	1			1		
		149	1	6	26	106	10
Percent by Urgency			.67	4.03	17.45	71.14	6.71

PROVIDER	SERVICE	TOTAL	Ext Urge	Urgent	Some Urge	No Urge	Unk
COMMUNITY MENTAL HEALTH CENTER							
428	P	30			30		
311	P	6		4	2		
231	P	3			1	2	
162	P	7			7		
		46	0	4	40	2	0
Percent by Urgency			0	8.70	86.96	4.35	0
CHILD DAY CARE CENTER							
337	B	37	10	27	0	0	0
Percent by Urgency			27.03	72.97	0	0	0
ADULT DAY CARE FACILITY							
1327	R	1	1				
428	R	1		1			
412	R	6					6
380	R	22		10	12		
261	R	2			1	1	
		32	1	11	13	1	6
Percent by Urgency			3.13	34.38	40.63	3.13	18.75
WORK ACTIVITY FACILITY							
208	S	5		1	3	1	
2011	S	11			11		
1761	S	5			5		
1759	S	5				5	
1449	S	3				1	2
1327	S	30	5	20	5		
1295	S	3			3		
432	S	5				5	
407	S	2			2		
394	S	14			14		
391	S	3		1	2		
386	S	1			1		
287	S	1				1	
261	S	1			1		
234	S	2			1	1	
318	S	5			5		
166	S	2			2		
196	S	2		2			
191	S	2		1	1		
165	S	2			2		
2071	S	7		7			
		111	5	32	58	14	2
Percent by Urgency			4.50	28.83	52.25	12.61	1.80
SHELTERED WORK FACILITY							
208	T	5			2	3	

PROVIDER	SERVICE	TOTAL	Ext Urge	Urgent	Some Urge	No Urge	Unk
2011	T	11			11		
1761	T	2			2		
1449	T	4		1	1	2	
1327	T	30		30			
1281	T	3			3		
483	T	7			7		
432	T	8			2	6	
425	T	10		1	9		
407	T	2			2		
394	T	54		8	46		
349	T	12		1	11		
323	T	13			13		
271	T	15	2	7	3	2	1
251	T	7			5	2	
174	T	28		4	5	7	12
330	T	40					40
415	T	30			30		
165	T	69		45	24		
1849	T	4			2	2	
		354	2	97	178	24	53
Percent by Urgency			.56	27.40	50.28	6.78	14.97
IN-HOME SERVICES (ALL KINDS-PRO & PARA PROFESSIONAL)							
2023	U	3			3		
254	U	29		2	21	6	
253	U	10	10				
2022	U	16	8	8			
317	U	1				1	
		59	18	10	24	7	0
Percent by Urgency			30.51	16.95	40.68	11.86	0
OTHER TO INCLUDE TRANSPORTATION, CAMPING							
1875	W	50					50
1590	W	11		2	5	3	1
1449	W	9			2	6	1
1128	W	1			1		
337	W	4		4			
221	W	20	2	15	3		
2002	W	10		10			
1478	W	2		1	1		
415	W	30			30		
		137	2	32	42	9	52
Percent by Urgency			1.46	23.36	30.66	6.57	37.96
ALL SERVICES		2196	83	416	767	595	335
PERCENT BY URGENCY			3.78	18.94	34.93	27.09	15.26